VOLUME I

RESEARCH COMPONENT

ILLNESS PERCEPTIONS AND PSYCHOLOGICAL WELL-BEING IN CANCER SURVIVORS

by

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OVERVIEW

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. The thesis consists of two volumes.

Volume 1: Research component

This volume comprises three chapters. The first chapter is a systematic literature review evaluating the existing research on the relationship between illness perceptions (also known as illness representations) and psychosocial outcomes in female cancer patients. Leventhal's Common Sense model of illness perceptions, also known as the self-regulatory model, is a theoretical model that explores how cognitive and emotional factors influence illness coping behaviours and a range of health outcomes (e.g. coping, psychological well-being, quality of life) (Hagger & Orbell, 2003; Leventhal, Brisette, & Leventhal, 2003). Psychosocial factors including psychological distress, coping, posttraumatic growth, fear of recurrence, quality of life, social and emotional support and changes in health practices were found to be related to one or more illness perception domains. A pattern of relationships between negative illness perceptions and poor psychosocial outcomes was found across studies. Psychological distress was the most frequently reported outcome whilst perceived consequences was the illness perception domain most commonly associated with psychosocial outcomes. The literature in this field however does not currently allow for a clear understanding of the specific psychosocial factors associated with each individual domain of the self-regulatory model in female cancer patients; future studies are necessary in order to clarify these relationships further. This paper has been prepared for submission to the journal Psycho-Oncology.

The second chapter is an empirical study that investigates the relationship between illness perceptions, resilience and psychological well-being in cancer survivors. It was hypothesised that those with a lower resilience and more negative illness perceptions would have a poorer quality of life and poorer psychological outcomes. Participants completed measures assessing their illness perceptions, psychological resilience, quality of life and psychological well-being. Results are in line with previous studies, showing that resilience and illness perceptions are significantly related to psychological well-being in cancer survivors. Cancer survivors may benefit from psychological interventions to address negative illness perceptions and increase psychological resilience. Further research is needed to confirm and expand on these findings. This paper has been prepared for submission to the journal Psycho-Oncology.

The third chapter is a public domain briefing document, providing and accessible summary of the literature review and empirical paper.

Volume 2: Clinical component

Five Clinical Practice Reports (CPRs) are presented in this volume. The first report details the case of a nine year-old girl referred to Child and Adolescent Mental Health Services with anxiety and is formulated from cognitive and systemic perspectives. Secondly, a service evaluation is presented exploring the views held by facilitators of parenting groups on their understanding of the role of, and the services provided by the parenting team who coordinate the groups. Thirdly, a single case experimental design is presented, which was used to evaluate the effectiveness of cognitive-behavioural therapy with a 49 year-old man with severe depression. The fourth report is a case study presented from an acceptance and commitment perspective of a woman with depression and a diagnosis of HIV. The fifth report is the abstract of an oral presentation of the use of reciprocal imitation training with a two and a half year-old girl with features of autism.

All names and identifying features have been changed to maintain confidentiality.

Dedication

To my mother, who has inspired me throughout my life and during this process, demonstrating incredible strength and resilience even at the very end of her life and has left me with the belief that with an open mind, determination and hard work anything is possible.

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CHAPTER ONE

LITERATURE REVIEW

ILLNESS PERCEPTIONS AND PSYCHOSOCIAL WELL-BEING IN FEMALE CANCER PATIENTS. A SYSTEMATIC REVIEW.

ABSTRACT

Objective: Illness perceptions refer to the way in which individuals think about their health problems and behave in response to them. This review systematically evaluated literature relating to the key psychosocial factors (quality of life, social and emotional support and psychological well-being) associated with illness perceptions in female cancer patients.

Method*:* A literature search using keywords was conducted with three databases: Medline, PsycINFO and EMBASE. Included studies presenting empirical findings focused on adult female cancer patients. A quality assessment was carried out for each study. A total of 16 studies were included in this review. The IPQ constructs and the psychosocial domains were used to organise the data extracted from the papers.

Results*:* Psychological distress was the most frequently assessed psychosocial outcome. While there is variability, there are indications of robust associations between identity, timeline, consequences, causal beliefs, control beliefs and psychological well-being (defined as psychological distress, coping and fear of recurrence).

Conclusions*:* A pattern of relationships between negative illness perceptions and poor psychosocial outcomes is evident across studies. Psychological distress was the construct most often measured in the studies and it was also the construct most frequently found to have a significant association with illness perceptions; perceived consequences was the illness perception most commonly associated with psychosocial outcomes. Little overlap between psychosocial factors and illness belief domains across studies made it difficult to generalise the findings. Further research is required in order to fully explain the relationship between individual illness perceptions and psychosocial outcomes in female cancer patients

INTRODUCTION

Cancer is among the leading causes of morbidity and mortality worldwide with 14 million new cancer diagnoses in 2012 and 8.2 million cancer-related deaths the same year (World Cancer Report, 2014). The most common cancers in women are breast, colorectum, lung, cervix, and stomach cancer (World Cancer Report, 2014). Breast cancer is by far the most common cancer in females with more than 464,000 new cases diagnosed in the UK in 2012 and accounting for almost a third of all female cases in the UK (Cancer Research UK, 2014). The next most common cancers in women are lung and bowel, each accounting for similar proportions of cases (12% and 11%, respectively) (Cancer Research UK, 2014). Advances in detection techniques, improved treatments and an ageing population have led to prevalence rates rising (DeSantis, Ma, Bryan & Jemal, 2014) and the rates of cancer survivors increasing by ~3% each year (Maddams, Brewster, Gavin, Steward, Elliott, Utley & Møller, 2009).

A diagnosis of cancer has a significant negative impact on mental health, quality of life (QoL), relationships and employment in both men and women (Avis, Crawford & Manuel, 2005; Burgess, Cornelius, Love, Graham, Richards & Ramirez, 2005; Sanda, Dunn, Michalski, Sandler, Northouse, Hembroff & Wei, 2008; Pitceathly & Maguire, 2003; Hofman, Ryan, Figueroa-Moseley, Jean-Pierre & Morrow, 2007). Adverse psychological consequences are frequently associated with cancer diagnoses and treatment, including depression, anxiety, post-traumatic stress disorder and fear of recurrence (McCorkle, Tang, Greenwald, Holcombe & Lavery, 2006; Amir & Ramati, 2002; Weitzner et al., 1997; Kornblith & Ligibel, 2003; Foster et al., 2009; Payne, Sullivan & Massie, 1996).

There are significant gender differences however in how men and women perceive their cancer diagnosis due to both social and biological differences, as well as the interaction between these factors (Friedman, 2011). From a biological perspective, some types of cancer are unique to one or other gender (e.g. gynaecological cancer or prostate cancer) and some differ in prevalence between genders. These gender differences can lead men and women to respond differently to a cancer diagnosis and women may have different needs compared to men coping with similar stressors (Vazquez, Gibson, & Kustra, 2007).

From a social perspective, social norms and gender roles give rise to different expectations of illness from men and women and can have an impact on the interpretation of symptoms and the formulation of illness perceptions (Friedman, 2011). For example, gender-biased stereotypes could lead to a misattribution of symptoms, different care-seeking behaviours and to different rates of diagnosis between male and female patients. Men with breast cancer, for example, tend to be diagnosed at an older age compared to women with the same diagnosis and tend to receive diagnoses of later-stage disease (Giordano, 2005). Therefore, the process of developing illness perceptions cannot be seen in isolation from the social differences in gender that are prevalent in society (Friedman, 2011). Another important effect of gender is that social constraints may lead to a person not taking appropriate action (even though they held illness perceptions that could have led to them taking appropriate action) (Benyamini, 2009). An example of this is that of women in traditional societies (societies characterised by an orientation to the past), for example in rural communities in Mexico, where at times, they are prohibited by their husbands from undergoing gynaecological examinations (Givaudan, Pick, Poortinga, Fuertes & Gold, 2005).

Research also suggests that there are sex differences in the process of symptom perception (Van Wijk et al., 1997). According to this research health surveys, studies on physical

symptom reporting and medical registration of physical complaints show that there are sex differences in symptom reporting, with women having the higher rates. According to Van Wijk et al. (1997) differences between men and women on these factors originate from early socialisation, traditional sex roles, and differences in social position. The authors discuss a symptom perception model that brings together factors and processes which are thought to affect symptom reporting, such as somatic information, selection of information through attention and distraction, attribution of somatic sensations, and the personality factors somatisation and negative affectivity (Van Wijk et al., 1997).

Research focusing on female cancer patients shows that there are a number of adverse psychological, medical and economic consequences of cancer survival and these often lead to negative psychosocial outcomes (Aziz 2002; Gotay & Muraoka 1998; Ganz 2001). A study analysing levels of anxiety and depression after cancer diagnosis showed that women reported higher rates of anxiety and depression compared to men, and for some cancer types the prevalence was two to three times higher in women (Linden, 2012). This finding was consistent with data in the general healthy female population where anxiety and depression rates are higher for women as compared to men (Piccinelli and Wilkinson, 2000). These differences may reflect a gender difference in willingness to report distress but could also reflect a tendency in women to use an emotional approach to coping and chose to express their emotions more than men (Goldzweig et al., 2009, Jacobs-Lawson et al., 2010; Linden, 2012; Stanton et al., 2000). Changes in social relationships have also been reported following cancer diagnosis and treatment, with some female survivors reporting fewer interactions with friends and relatives (Bloom, Stewart, Chang & Banks, 2004) and others reporting a lack of social and emotional support (Wyatt & Friedman 1996). Another significant challenge faced by women with cancer is the impact of changes to their body and appearance, which can act

as constant reminders of the disease and its treatment (Harcourt & Frith, 2008) and can also impact on and lead to changes in relationships. This is particularly challenging in a society in which women value their physical appearance and it gives them a significant sense of self-worth (White, 2000). Physical appearance (e.g. hair loss following cancer treatment) can act as a visible indicator of a woman's disease and therefore it is seen as a confirmation of identity as a cancer patient (Harcourt & Frith, 2008; Rosman, 2004).

In a study by Carelle et al. (2002) patients ranked side effects related to body image (e.g. such as hair loss, weight loss, and loss of sexual interest) among the most severe side effects of their chemotherapy treatments. However, female patients with cancer placed more emphasis on appearance and sexually related side effects than did male patients (Carelle et al., 2002). In a study comparing male and female cancer survivors responses relating to their physique and perceived sexual appeal, women reported dislikes with their body image more often than men (DeFrank et al., 2007). The same study also found that sexual dysfunction was not associated with body image for men whilst female body image was strongly associated with sexual functioning (DeFrank et al., 2007).

Long-term physical health problems and poorer physical and role functioning have been associated with poorer QoL outcomes (e.g. poorer emotional health, sexual health and pain) in female cancer patients (Casso *et al.* 2004). QoL has also been found to vary according to treatment type (Foster, Wright, Hill, Hopkinson & Roffe, 2009) with more advanced stage of cancer associated with poorer QoL (health, socioeconomic, psychological/spiritual functioning) in breast cancer survivors (Weitzner, Meyers, Stuebing & Saleeba, 1997).

Psychosocial interventions have been shown to lead to positive outcomes in the general oncology population (Rehse, & Pukrop, 2003; Sheard & Maguire, 1999). These include

support groups, individual psychotherapy, imagery, social support, psychoeducation and cognitive behavioural therapies (Groarke, Curtis & Kerin, 2013; Manne, Ostroff & Winkel, 2007). Increasing research in female cancer patients shows that, to support cancer patients' psychosocial well-being it is important to understand patients' cognitive representations of disease and associated coping mechanisms (Cameron, Leventhal & Love, 1998; Millar, Purushotham, McLatchie, George & Murray, 2005; Scharloo, Baatenburg, Langeveld, van Velzen-Verkaik, Doorn-op den Akker & Kaptein, 2005).

There are several theoretical models within the field of health psychology that could be applied to the understanding of patients' cognitive representations. One such model is Leventhal's Common Sense model (CSM). This model is of particular interest for a number of reasons; it is a useful model for eliciting and understanding patients' beliefs about their cancer since it is structured around key domains including perceptions regarding identity, cause, timeline, consequences, cure/control and emotional representations. These are important constructs in cancer since it is assumed that individuals represent their condition on this set of dimensions (Hagger & Orbell, 2003) and these dimensions have been validated in numerous studies and can be regarded as the core components of illness representations (Hagger & Orbell, 2003; Heijmans & De Ridder, 1998; Weinman et al., 1996). Additionally, since its development over 30 years ago, the CSM has provided health workers and researchers with a useful and clear framework for helping to understand the role of cognitive factors in response to and in the management of a wide variety of illnesses (Hagger & Orbell, 2003). A strength of the model is that it conceptualises patients as problem solvers who take an active role in the management of their health. The increase in research investigating illness perceptions across illnesses has been further facilitated by the development of a tool used to

reliably assess illness perceptions: the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996).

Leventhal's Common Sense model of illness perceptions, also known as the self-regulatory model, is a theoretical model that explores how cognitive and emotional factors influence illness coping behaviours and a range of health outcomes (e.g. coping, psychological well-being, quality of life) (Hagger & Orbell, 2003; Leventhal, Brisette, & Leventhal, 2003). According to this model, when individuals are faced with a health threat, they create representations from prior knowledge and past experiences of their illness (also called illness perceptions, cognitive representations or schema), which enable them to make sense of their symptoms and guide any coping actions (Hale, Treharne & Kitas, 2007). Illness perceptions are seen to guide the decisions people make around developing action plans, managing their treatment regimens and influence their coping strategies. These coping strategies in turn have an impact on the individual's illness outcomes and emotional well-being (Leventhal, Halm, Horowitz, Leventhal & Ozakinci, 2005).

Leventhal et al. (1997) described a consistent pattern in the way patients structure their perceptions of illness. Firstly there is an *identity* component, which refers to the label or name given to the condition and the statements regarding beliefs about what symptoms arise from the condition (Hagger & Orbell, 2003). Research has found that people are often likely to interpret diverse symptoms as evidence of the label and identity beliefs have been found to influence the process of adjustment (Meyer, Leventhal, & Gunman, 1985). For example, in a study looking at adjustment and coping in women with breast cancer, Millar et al. (2005) found that the perceived impact of symptoms was a significant predictor of distress both in the cross-sectional and prospective analyses. These identity beliefs have been found to influence a number of outcomes including decision-making, coping behaviours, health-

management and early-detection behaviours across physical health populations (Rutter & Rutter, 2002; Houldin, Jacobsen & Lowery, 1996).

Patients also hold beliefs about the perceived cause of illness; covered by the *cause* component of the model. The causal beliefs may include biological, emotional, psychological and/or environmental factors and these may not be completely bio-medically accurate. They are based on information gathered from individual experience, conversations with other people, the media and health professionals (Hale et al., 2007). Furthermore, illness perception components include individuals' beliefs about the course of the illness (how long the condition might last, whether it will be acute or chronic and the time scale of illness symptoms); this is referred to as the *time-line* dimension. More recently a *cyclical time-line* component was also added to the time-line dimension; this refers to beliefs about fluctuations in the symptoms and the temporal variability of the illness (this subscale is helpful when working with individuals whose illness cannot be adequately captured on a simple acute/chronic dimension such as menstrual disorders, skin conditions and some auto-immune disorders) (Moss-Morris et al., 2002).

The beliefs a person has about the consequences of the illness to their life (physically and socially) and the impact on their functioning are known as the *consequences* dimension. Lastly, the *curability/controllability* dimension refers to the beliefs about whether the condition can be cured or kept under control (e.g. beliefs around the efficacy of treatment or beliefs around the individual's role in playing a part in controlling their illness).

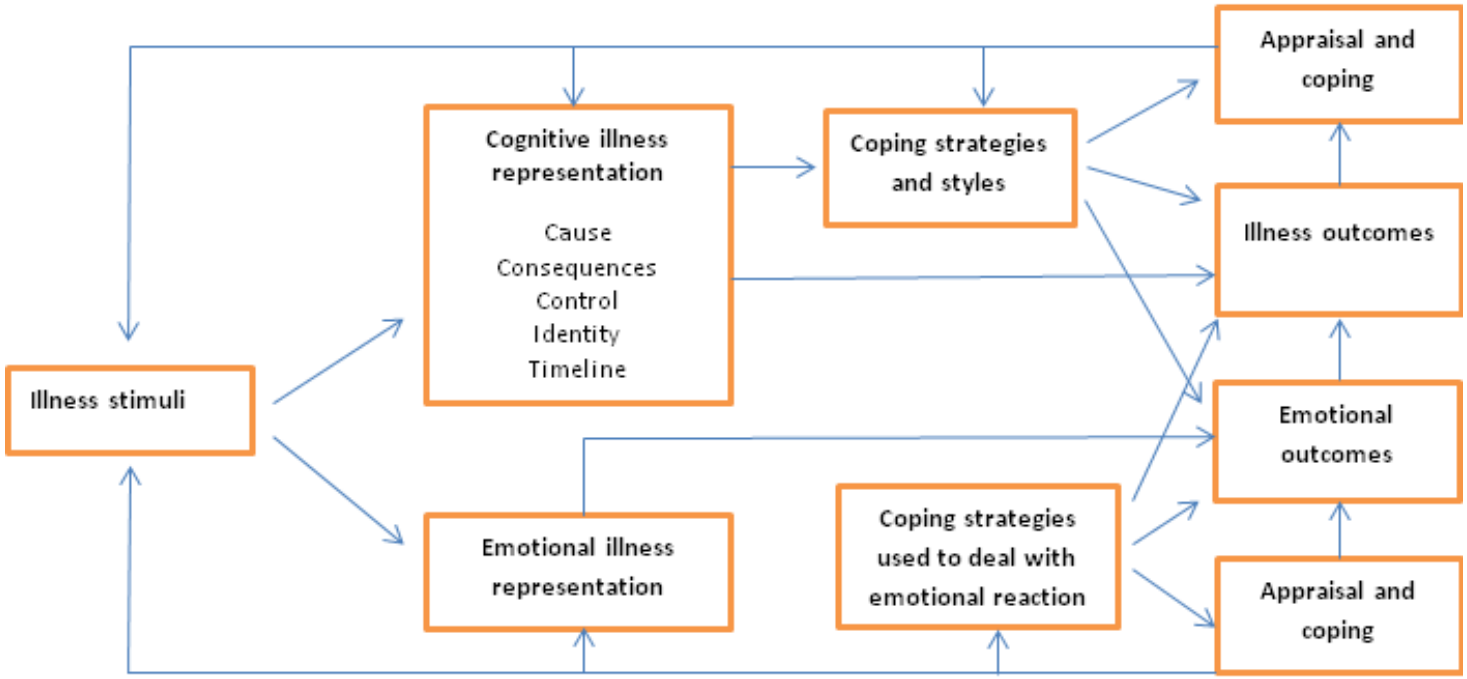


Figure 1. Common Sense Model of Illness Cognitions (Rozema, Vollink & Lechner, 2009; Hagger & Orbell, 2003)

The CSM model is described as the 'parallel-processing' model since people are assumed to make simultaneous cognitive and emotional representations of their illness (Leventhal, Meyer & Nerenz, 1980) and these may be important in leading to emotional outcomes (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002) (see Figure 1). As people experiencing a physical health condition obtain new information about their illness and evaluate their attempts to cope with its effects, new illness perceptions are created and develop based upon these experiences. Illness perceptions derive from a number of sources, i.e. personal experiences, information obtained from others and from health professionals, which integrate with existing beliefs and knowledge that people hold, enabling them to make sense of their symptoms and guide their behaviours. As new information becomes available, illness perceptions may change, may be discarded or adapted, or new illness perceptions may be created (Hale et al., 2007). Such beliefs, however, can differ significantly from the medical view of an illness (Kaptein et al., 2010). Illness perceptions are associated with coping strategies, behaviours and action plans (such as changing dietary content) and outcomes (Hale et al., 2007; Hale, Treharne, Macey & Kitas, 2006).

The increase in research investigating illness perceptions across illnesses was facilitated, in part, by the development of a tool used to reliably assess illness perceptions: the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996). A revised version of the IPQ was later developed with three additional sub-scales (*timeline cyclical, coherence and emotional representation*) and the separation of the cure/control dimension into two separate dimensions: *treatment control and personal control* (IPQ-R; Moss-Morris et al., 2002). Emotional representation refers to emotional responses generated by an illness and illness coherence refers to whether the patient feels that they understand the illness, or if it appears to them as mysterious and incomprehensible (Moss-Morris et al., 2002). More

recently a shorter version of the IPQ-R has been developed, the Brief Illness Perception Questionnaire (BIPQ), which has good reliability and validity (in asthma, renal and diabetes outpatients) (BIPQ; Broadbent, Petrie, Main & Weinman, 2006).

There is growing evidence illustrating strong relationships between illness perceptions and physical and psychological health outcomes (Cameron & Moss-Morris, 2004; Dorrian, Dempster & Adair, 1999). Meta-analyses and reviews have been carried out looking at illness perceptions across a number of physical health conditions (e.g. Hagger & Orbell, 2003; Foxwell et al., 2013; Parfeni et al., 2013). These have illustrated that an individual's knowledge about their symptoms (identity)**,** their belief in the controllability of their illness (personal control) and their belief in the appropriateness and effectiveness of the treatment (treatment control) are associated with more adaptive outcomes of psychological well-being and social functioning. On the other hand, more negative and unhelpful beliefs were related to more maladaptive outcomes (e.g. poorer social and role functioning and psychological distress) (Hagger & Orbell, 2003; Hampson, 1997; McSharry, Moss-Morris, & Kendrick, 2011). Furthermore, according to Hagger and Orbell's (2003) meta-analytic review of patients across a number of physical health populations, more positive perceived consequences and a weaker illness identity have been associated with poorer adaptive psychological outcomes including social, physical and psychological well-being.

Studies in cancer patients have found that negative illness perceptions predicted worse health-related quality of life and depression after treatment (Chaboyer, Lee, Wallis, Gillespie & Jones, 2010; Traeger, Penedo & Gonzalez 2009). With regards to illness perceptions in the female cancer population, Rabin, Leventhal, and Goodin (2004) found that breast cancer patients reported increased anxiety, depression and fear of recurrence when they believed that their cancer timeline was chronic or cyclical. Additionally, research suggests that illness

perceptions are associated with both general distress and quality of life in breast cancer patients (Jorgensen, Frederiksen, Boesen, Elsass & Johansen, 2009; Millar et al., 2005; Rabin et al., 2004), however there is considerable variation across these studies in terms of the illness domains being measured. In addition, specific causal beliefs about cancer (beliefs around altered immunity), as well as illness related distress and avoidant coping styles, predicted psychosocial support group attendance (Cameron, Booth, Schlatter, Ziginskas, Harman & Benson, 2005).

These relationships between illness perceptions, psychological states and coping have led researchers to carry out theoretically guided investigations into the ways in which people understand and cope with illness with the aim of developing treatment programmes designed to change inaccurate and negative illness perceptions and improved outcomes. Petrie, Cameron, Ellis, Buick and Weinman (2002) tested whether a brief psychological hospital-based intervention designed to change illness perceptions of myocardial infarction would result in changes in outcomes; it was found that following the intervention, patients returned to work earlier compared to those who had not attended the group and their reported rates of symptoms were significantly less frequent. Cognitive behavioural approaches have also been used to change illness-related cognitions and have been found to mediate treatment related improvements and improve psychological well-being (in patients with irritable bowel syndrome and in patients with prostate cancer) (Chilcot & Moss-Morris, 2013; Traeger, Penedo, Benedict, Dahn, Lechner, Schneiderman, & Antoni, 2013).

A number of research studies in female cancer patients over the past two decades have looked at the relationship between illness perceptions and factors such as physical and psychological well-being, quality of life, psychosocial adjustment and engagement in treatment (Cameron et al., 2005; Jorgensen, et al. 2009; Millar et al., 2005; Silva, Moreira & Canavarro, 2012) and

researchers are starting to gain an understanding of some of the factors associated with illness perceptions within this specific population. Increasingly, studies suggest that women's illness perceptions (Costanzo, Lutgendorf, Bradley, Rose & Anderson, 2005; Gould, Brown & Bramwell, 2010), and their coping responses (Costanzo, Lutgendorf, Rothrock & Anderson 2006; Gould et al., 2010), influence psychological outcomes (Gould et al., 2010).

Despite the availability of studies that have looked at illness perceptions in male and female populations, no previous literature review has explored the relationship between illness perceptions and psychosocial factors (psychological distress, coping, posttraumatic growth, fear of recurrence, quality of life, social and emotional support and changes in health practices) in female cancer patients.

Given that the process of developing illness perceptions and the actions that are consequently taken in response to these perceptions are influenced by biological and social differences between men and women (Benyamini, 2009), this review focused on illness perceptions and psycho-social well-being in female cancer patients in particular. This review is required in order to further our understanding of these individual illness perception domains and their relationship with psychosocial outcomes in this population. Additionally, research in this area will be helpful in the identification of 'at-risk' groups and in the further development of interventions targeted at generating less negative and more realistic illness perceptions.

METHOD

Search Strategy

Guidelines produced by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) for the identification of articles for review were used to develop search criteria (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

Three methods were used to identify relevant studies: a keyword search, a backward search and a forward (citation) search (Figure 2). Literature searches were performed using three electronic databases: Medline (1946 – September 2014), PsycINFO (1967 – September 2014) and EMBASE (1974 – September 2014). The search terms were grouped into cancer terms (cancer, oncolog*, neoplasm*) and illness perception terms (illness cognition*, illness representation*, illness perception*, illness belief*, self regulat* model, common sense model*). Terms relating to cancer were then combined using OR, as were terms relating to illness perceptions. The combined cancer and illness perception terms were further combined using the AND function. Titles and abstracts of the full list of identified studies were read and, if suitable, a full-text copy was retrieved and assessed against inclusion/exclusion criteria. Duplicates were excluded. A backward search was then performed, which involved hand searching the reference lists of included articles. A forwards (citation) search was then conducted.

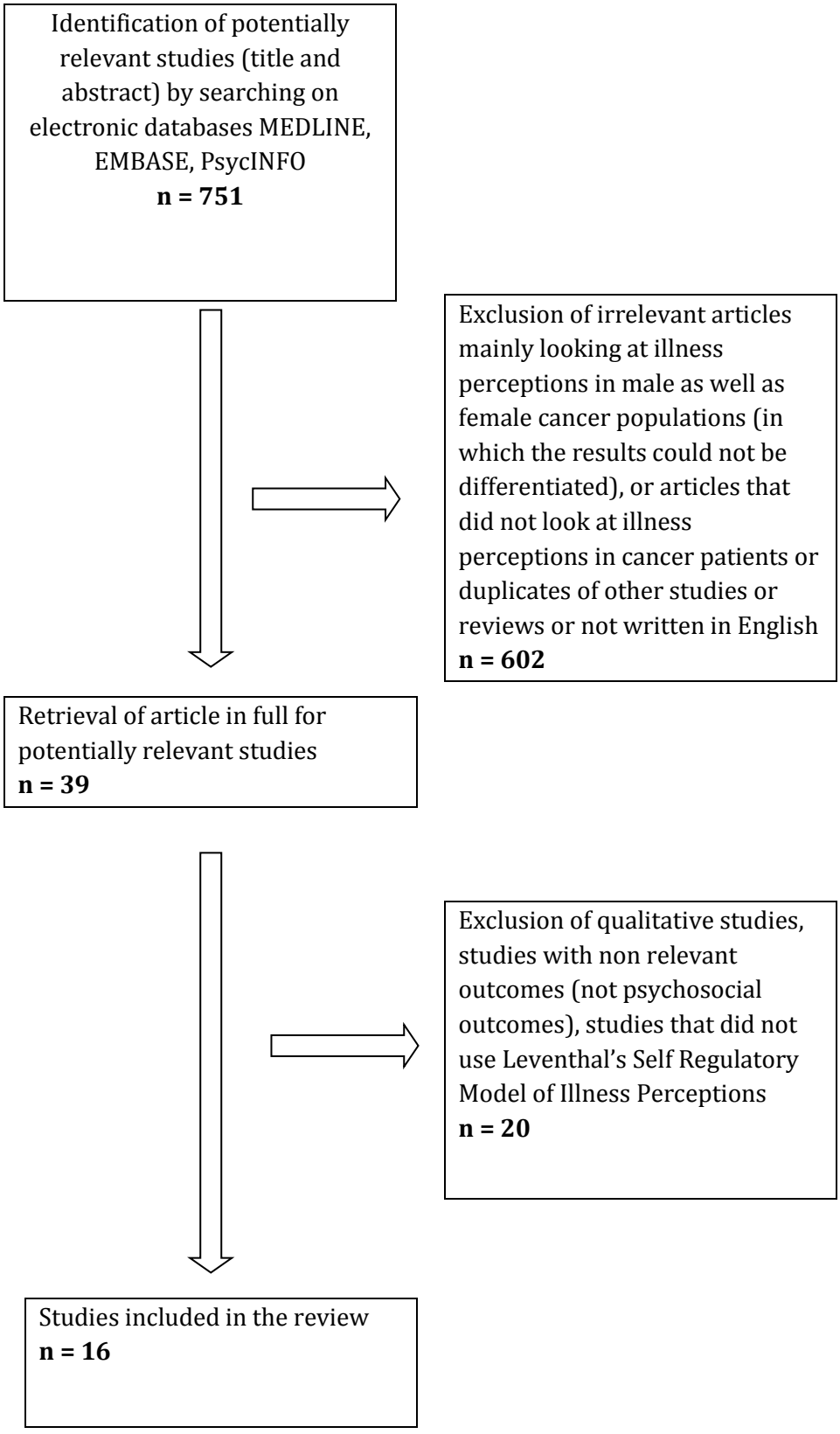
Studies were included based on the inclusion/exclusion criteria shown below. Results sections were examined and psychosocial factors associated with illness perceptions in female cancer patients compiled. This allowed all studies that concerned a certain factor to be grouped together and to be considered in relation to each other.

Inclusion and exclusion criteria

Articles that met the following criteria were included in the review: (1) included female participants (age > 18) who had received a diagnosis of any type of cancer, (2) were empirical studies, (3) were based on Leventhal's Self-Regulation or Common Sense model to conceptualise illness perceptions, (4) presented information on one or more of the following psychosocial outcomes: psychological well-being (psychological distress, coping, posttraumatic growth, fear of recurrence), quality of life, social and emotional support or changes in health practices, (5) studies involving male participants, if the data from males and females could be differentiated. Studies were excluded from the review if they reported data on both female and male cancer patients that could not be differentiated; if they were not empirical studies (commentaries, dissertation abstracts, books, case studies, conference abstracts), and if the studies were not published in English. The articles included in the review therefore included females with different cancer diagnoses (breast, cervix, gynaecological and lung) and at different stages of their cancer journey (some with non-metastatic cancer and receiving curative treatment and some at the palliative stage of care).

A total of 16 papers were included within the final review.

Figure 2. PRISMA diagram of search strategy



Quality assessment

A standard quality checklist of 11 items (Kmet, Lee & Cook, 2004) (Appendix A) was used to assess the extent to which each study fulfilled a pre-existing set of criteria. The broad nature of the quality assessment allowed a range of methodologies to be assessed. Studies were rated according to the method outlined by Crist and Grunfeld (2013). Studies were scored depending on whether they met each criterion (Table 1) (yes = 2, partially = 1 and no = 0). If a criterion was not applicable, then it was excluded from the score calculation. A 'total sum' score was calculated by summing the 'yes' and 'partial' scores. The 'total possible sum' was calculated as possible responses (excluding n/a responses) multiplied by two. Finally, a 'summary score' was obtained by dividing the 'total sum' by the 'total possible sum', reflecting the overall methodological quality. Studies were categorised as high quality (score of 17 or above), moderate quality (11 to 16) or low quality (10 or less) (Crist & Grunfeld, 2013).

Analytic approach

The IPQ constructs of identity, cause, timeline, consequences, control, emotional representations and coherence were used to organise the data extracted from the papers. This data was additionally organised according to the psychosocial domains of 'psychological wellbeing', 'quality of life', 'social and emotional support' and 'changes in health practices'. This information was extracted from the studies by identifying whether the outcome measures and results of the studies fitted into these psychosocial categories and was organized as presented in Table 4.

RESULTS

Description of studies included

From the electronic search 751 potentially relevant articles were identified; of these, 16 studies fulfilled the inclusion and exclusion criteria (see Figure 2). The majority of the studies were classified as high quality, two as moderate quality and none as low quality (Table 1). Twelve studies used cross-sectional designs, three prospective designs and one an exploratory design using a combination of data from two studies (a randomized controlled trial and a descriptive study which were both part of a longitudinal study). Twelve studies focused on breast cancer, two on cervical cancer, one on gynaecological cancer (including cervical, endometrial, ovarian and vulvar cancers) and one focused on breast, gynaecological (type not specified) and lung cancer. Across the studies, five illness perception measures were used; the IPQ-R (n = 9), B-IPQ (n =3), IPQ (n =1), a questionnaire developed by the authors based on the IPQ (n=2), and one study used only the timeline sub-scale from the IPQ. Total sample size across all studies was 2007 (range: 61 to 371). Studies were carried out across eight countries (e.g. UK, Denmark, New Zealand, USA, Portugal, India, The Netherlands and Australia). Participants were predominantly White females. Eleven studies reported 'psychological distress' outcomes such as depression and anxiety in relation to one or more of the illness perception subscales (Millar et al., 2005; Jorgensen, et al., 2009; Cameron et al., 2005; Silva et al., 2012; Awasthi & Mishra, 2006; Awasthi & Mishra, 2010; Henselmans, Sanderman, Baas, Smink & Ranchor, 2009; Gould et al., 2010; Rozema et al., 2009; Duric, Butow, Sharpe, Boyle, Beith, Wilcken, Heritier, Coates et al., 2007; Mc Corry Dempster, Quinn, Hogg, Newell, Moore, Kelly & Kirk, 2013), one study reported 'coping' outcomes (Rozema et al., 2009), one study reported 'posttraumatic growth' outcomes (Silva et al., 2012), two

studies reported ‘fear of recurrence outcomes’ (Corter, Findlay, Broom, Porter & Petrie, 2013; Rabin et al., 2004), three studies reported ‘quality of life’ outcomes (Croom, Hamann, Kehoe, Paulk & Wiebe, 2013; Jorgensen et al., 2009; Silva et al., 2012), three studies reported ‘changes in health practices’ outcomes (Croom et al., 2013; Duric et al., 2007; Costanzo et al., 2011) and four studies reported ‘social and emotional support’ outcomes (Awasthi et al., 2006; Awasthi et al., 2010; Iskanarsyah, de Klerk, Suardi, Soemitro, Sadarjoen & Passchier, 2013; Cameron et al., 2005). These outcomes were categorised according to whether they related to the identity, cause, timeline, consequence, control, emotional representation or coherence subscales of the IPQ (see Tables 3 and 4). The measures that were used to assess psychological well-being, quality of life, social and emotional support and changes in health practices are listed in Table 2.

Table 1. Summary of studies

Authors, date and country	Study design	Sample size, cancer type (s)	Measure of Illness Perceptions	Quality rating
Millar et al. (2005), UK	Prospective	371, breast	Illness Perception Questionnaire	High
Jorgensen et al. (2009), Denmark	Exploratory	177, breast	Revised Illness Perception Questionnaire	High
Cameron et al. (2005), New Zealand	Prospective	110, breast	Revised Illness Perception Questionnaire	High
Costanzo et al. (2011), USA	Prospective	79, breast	Revised Illness Perception Questionnaire	High
Silva et al. (2012), Portugal	Cross–sectional	78, breast	Brief Illness Perception Questionnaire (Portuguese version)	High
Awasthi et al. (2006), India	Cross–sectional	100, cervix	Illness causation, consequences, controllability beliefs measure and outcome brief measure	Mod
Awasthi et al. (2010), India	Cross–sectional	100, cervix	Illness causation, consequences, controllability beliefs measure and outcome brief measure	Mod
Henselmans et al. (2009), The Netherlands	Cross–sectional	242, breast	Revised Illness Perception Questionnaire	High
Gould et al. (2010), UK	Cross–sectional	61, gynaecological	Revised Illness Perception Questionnaire	High
Rozema et al. (2009), The Netherlands	Cross–sectional	119, breast	Revised Illness Perception Questionnaire	High
Rabin et al. (2004), USA	Cross–sectional	69, breast	Measure to assess perceived timeline of cancer	High
Corter et al. (2013), New Zealand	Cross–sectional	153, breast	Brief Illness Perception Questionnaire	High
Duric et al. (2007), Australia	Cross–sectional	83, breast	Revised Illness Perception Questionnaire	High
Mc Corry et al. (2013), UK	Cross–sectional	90, breast	Revised Illness Perception Questionnaire	High
Iskanarsyah et al. (2013), The Netherlands	Cross–sectional	70, breast	Brief Illness Perception Questionnaire	High
Croom et al. (2013), USA	Cross–sectional	105, breast, gynaecological, lung	Revised Illness Perception Questionnaire	High

Table 2. Assessment measures used in each study

Domains	Assessments included in systematic review	Studies
Psychological wellbeing	**Psychological distress**	
	General Health Questionnaire (GHQ)	Millar et al. (2005)
	Profile of Mood States (POMS – SF)	Jorgensen et al. (2009); Gould et al. (2010)
	Hospital Anxiety and Depression Scale (HADS)	Silva et al. (2011); Rabin et al. (2004); Corter et al. (2012); Duric et al. (2007); McCorry et al. (2013)
	Spielberger State Trait Anxiety Inventory (STAI)	Cameron et al. (2005); Henselmans et al. (2010); Duric et al. (2007)
	Center for Epidemiologic Studies Depression (CES-D) Scale	Cameron et al. (2005); Henselmans et al. (2010)
	Cancer Worries Scale	Henselmans et al. (2010)
	RAND-36 (Dutch translation)	Rozema et al. (2009)
	Impact of Events (IOE)	Duric et al. (2007)
	Revised Impact of Events Scale (RIES)	Cameron et al. (2005)
	Coping	
	Mental Adjustment to Cancer Scale (MAC)	Millar et al. (2005)
	Question ("what should one do in order to manage cancer?")	Awasthi et al. (2006)
	COPE	Gould et al. (2010)
	Utrecht Coping Questionnaire (UCL)	Rozema et al. (2009)
	Revised Life Orientation Test (LOTr)	Duric et al. (2007)
	Cancer Coping Questionnaire	McCorry et al. (2013)
	Posttraumatic growth	
	Posttraumatic Growth Inventory (Portuguese version)	Silva et al. (2011)
	Fear of Recurrence	
	A Fear of Reccurence Scale based on a scale assessing fear of ovarian cancer	Rabin et al. (2004)
	Worry about Cancer Scale	Corter et al. (2012)
Quality of life	EORTC Quality of Life C30	Jorgensen et al. (2009)
	WHOQOL-Bref	Iskandarsyah et al. (2013)
	QoL-BREF (WHOQOL-Bref) (Portuguese version)	Silva et al. (2011)
	The Functional Assessment of Cancer Therapy General scale (FACT-G)	Croom et al. (2013)
Social and emotional support	Social Network Measure	Cameron et al. (2005)
	Social Support Measure	Awasthi et al. (2006); Awasthi et al. (2010)
	Sarason's Social Support Questionnaire (SSQ)	Duric et al. (2007)
	Social Support Behaviours Scale	Cameron et al. (2005)
Changes in health practices	Self –reported changes following cancer diagnosis	Costanzo et al. (2011)

Psychosocial factors associated with each dimension of illness perceptions are discussed, with the aim of ascertaining the extent to which psychosocial factors (e.g. psychological distress, coping, posttraumatic growth, fear of recurrence, quality of life, changes in health practices and social and emotional support) are associated with illness perceptions in female cancer patients (see Table 3). A summary of results is presented in Table 4.

Table 3. Main factors examined in relation to illness perceptions

	Identity	Cause	Timeline	Consequences	Control	Emotional representations	Coherence
Psychological distress	Milllar et al. (2005); Rozema et al. (2009); Duric et al. (2007); McCorry et al. (2013)	Jorgensen et al. (2009); Cameron et al. (2005); Awasthi et al. (2010); McCorry et al. (2013)	Milllar et al. (2005); Gould et al. (2010); Rabin et al. (2004); McCorry et al. (2013)	Silva et al. (2011); Awasthi et al. (2006); Gould et al. (2010); Rozema et al. (2009); McCorry et al. (2013)	Henselmans et al. (2010); Gould et al. (2010); Rozema et al. (2009); McCorry et al. (2013)	Rozema et al. (2009)	Gould et al. (2010); McCorry et al. (2013)
Coping		Rozema et al. (2009)	Rozema et al. (2009)		Rozema et al. (2009)	Rozema et al. (2009)	
Post-traumatic growth				Silva et al. (2011)			
Fear of Recurrence	Corter et al. (2012)	Corter et al. (2012)	Rabin et al. (2004); Corter et al. (2012)	Corter et al. (2012)	Corter et al. (2012)		
Quality of Life	Croom et al. (2013)			Jorgensen et al. (2009); Silva et al. (2013)	Jorgensen et al. (2009)		
Social and Emotional Support		Awasthi et al. (2010); Cameron et al. (2005);		Awasthi et al. (2006); Awasthi et al. (2010)	Awasthi et al. (2010); Iskanarsyah et al. (2013)	Iskanarsyah et al. (2013)	
Changes in health practices	Duric et al. (2007)	Costanzo et al. (2011)	Costanzo et al. (2011)	Costanzo et al. (2011); Duric et al. (2007); Croom et al. (2013)	Costanzo et al. (2011)		Croom et al. (2013)

Table 4. Summary of results for each study presented according to illness perception domains

	Identity	Cause	Timeline	Consequences	Control	Emotional representat.	Coherence
Millar et al. (2005)	**Psychological distress:** Identity was a predictor of distress at 3, 6 and 12 months following breast surgery (3 months β=0.67**; 6 months β= 0.83**; 12 months β=0.44*)	Cause as a predictor of psychological distress was not assessed	**Psychological distress:** Timeline was a predictor of distress at 6 and 12 months following breast surgery (6 months β=-0.90*; 12 months β= -0.76*) (i.e. the shorter the perceived timeline of the illness the greater the distress).	Consequences as a predictor of psychological distress was not assessed	Control as a predictor of psychological distress was not assessed	Not assessed	Not assessed
Jorgensen et al. (2009)	Identity was not reported as a significant factor explaining variance in Quality of Life or Distress.	**Psychological distress:** Causal beliefs about stress or worry explain 22% of variance in general distress (F = 4.57*). Higher levels of general distress associated with a stronger belief that stress or worry caused the illness (β = 4.11)	Timeline was not reported as a significant factor explaining variance in Quality of Life or Distress.	**Quality of life:** Higher quality of life was associated with a perception of less severe consequences (β = -1.37)	**Quality of life:** Higher quality of life was associated with a perception of higher treatment control beliefs (β = 1.41) – no longer significant once controlled for demographic variables	Not assessed	Not assessed

Table 4. Continued

	Identity	Cause	Timeline	Consequences	Control	Emotional representat.	Coherence
Cameron et al. (2005)	Not assessed	**Psychological distress:** Causal beliefs about altered immunity and stress positively correlated (r = .32*) **Social and emotional support:** Altered immunity causal beliefs and distress were associated with a higher propensity to participate in a support group (β = .10*). **Stress causal beliefs did not predict support group participation**.	Not assessed	Not assessed	**Social and emotional support: control beliefs did not predict support group participation**.	Not assessed	Not assessed
Costanzo et al. (2011)	Not assessed	**Changes in health practices:** Causal beliefs linked to diet were associated with increase in consumption of fruits and vegetables (Wald $\chi^2(1) = 5.10$*) and decreased fat intake (Wald $\chi^2(1) = 5.84$*). Causal beliefs linked to lack of exercise were associated with increased physical activity (Wald $\chi^2(1) = 3.90$*) by three months post-treatment. Causal beliefs about cancer linked to stress or worry were associated with avoidance of stressful situations at three weeks (Wald $\chi^2(1) = 3.12$*) and three months post-treatment (Wald $\chi^2(1) = 3.12$*). There were no significant relationships between attributing cancer to alcohol use and decreased alcohol consumption.	Changes in health practices: Timeline beliefs were not associated with any changes in health practices.	**Changes in health practices:** Women who perceived more severe consequences of their cancer at 3 weeks post-treatment were more likely to report increasing the frequency with which they avoided stress by three months post-treatment (Wald $\chi^2(1) = 441$*). Perceptions of disease consequences did not significantly predict changes in fat consumption, physical activity or alcohol use.	**Changes in health practices: Personal control was not significantly associated with concurrent (3 weeks post-treatment) or prospective (3 months post–treatment) changes in health practices.**	Not assessed	Not assessed

Table 4. Continued

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	Identity	Cause	Timeline	Consequences	Control	Emotional representat	Coherenc e
Silva et al. (2012)	Not assessed	Not assessed	Not assessed	**Psychological distress:** Negative perceptions of consequences significantly associated with higher emotional distress (depression: r = .43**; anxiety: r = .49**). **Quality of Life:** Negative perception of consequences significantly associated with impaired physical and psychological QoL (r = -.42** and r = -.32* respectively). **Posttraumatic growth:** PTG moderated the relationships between negative perceptions of the consequences of breast cancer and quality of life, acting as a stress-buffering mechanism. Among women who perceived breast cancer as having a more negative impact on their lives, higher PTG buffered this negative perceived impact on psychological and social quality of life ($p<0.01$) and also on depression ($p<0.06$). **This effect was not found for physical QOL and anxiety.**	Not assessed	Not assessed	Not assessed
Awasthi et al. (2006)	Not assessed	No results reported related to psychosocial outcomes.	Not assessed	**Social and emotional support:** Emotional, informational, social and practical support negatively correlated with consequences indicating that greater the level of social support, the consequences of illness were perceived to be less severe.	**Social and emotional support:** Patients who scored higher on the social support measure held stronger beliefs in "self" and "doctor" for illness control than those who scored lower on the social support measure. Differences between these groups were significant with respect to self (t = 3.66**) and doctor (t = 2.97**).	Not assessed	Not assessed

Table 4. Continued

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	Identity	Cause	Timeline	Consequences	Control	Emotional representat.	Coherence
Awasthi et al. (2010)	Not assessed	**Social and emotional support:** Individual, psychosocial and supernatural causes negatively correlated with emotional, informational, social companionship and practical support (i.e. women who received less support believed more strongly in these causes of cancer).	Not assessed	**Social and emotional support:** Practical support, doctor-control and supernatural control accounted for approximately 49% of the variance in score on the interpersonal consequences measure (F= 30.92**). Practical support accounted for approximately 40% of the variance (F= 65.14**) in scores. Overall support (β=-.44), "doctor" control (β=-0.27) and supernatural causes (β= .17) explained approximately 41% of the variance in scores on psychological consequences.	**Social and emotional support:** "Self" control negatively correlated with informational and social companionship support and positively with practical support. "Doctor" control was positively correlated with emotional, informational, social companionship and practical support.	Not assessed	Not assessed
Henselmans et al. (2009)	Not assessed	Not assessed	Not assessed	Not assessed	**Psychological distress:** women with a strong sense of personal control over events and situations in life reported less anxiety (β=-.19*) two months after the end of treatment, controlling for baseline.	Not assessed	Not assessed

Table 4. Continued

	Identity	Cause	Timeline	Consequences	Control	Emotional representat.	Coherence
Gould et al. (2010)	Not assessed	Not assessed	**Psychological distress:** Denial and disengagement coping mediate paths between perceptions of a cyclical timeline and higher POMS Total scores (β= .30*). The reverse mediation path, from POMS to cyclical timeline was not significant (POMS to denial/dis. β= .45, *p*<0.01, denial/dis. to cyclical timeline β= .18, *p*=.235)	**Psychological distress:** Consequences correlated with POMS total (r = .42**) (where the greater the perceived consequences, the greater the POMS score).	**Psychological distress:** Personal control correlated with POMS total (r = -.30*) and treatment control correlated with POMS total (r = -.31*)	Not assessed	**Psychological distress:** Denial and disengagement coping mediate paths between perceptions of coherence and higher POMS Total scores (β= -.45**). The reverse mediation path, from POMS to coherence was not significant (POMS to denial/dis. β= .45, *p*<0.01, denial/dis. to cyclical timeline β= -.26, *p*=.054)
Rozema et al. (2009)	**Psychological distress:** Identity correlated negatively with mental health (r = -.428*) **Coping:** Identity related to cognitive and behavioural avoidance as a coping strategy (r = .195* and r = .205* respectively). Identity did not significantly explain any variance in the scores of problem-focused coping.	**Coping:** Psychological cause related to behavioural avoidance as a coping strategy (r = .212*). Psychological cause had a significant negative relation with problem-focused coping (β = -.30**).	**Coping:** Timeline correlated negatively to cognitive and behavioural avoidance as a coping strategy (r = -.222** and r = -.335** respectively). Timeline did not significantly explain any variance in the scores of problem-focused coping. **Psychological distress:** Timeline (acute/chronic) correlated negatively with mental health (r = -.352**).	**Coping:** Consequences did not significantly explain any variance in the scores of problem-focused coping. **Psychological distress:** Consequences correlated negatively with mental health (r = -.438**).	**Psychological distress:** Personal control showed a positive correlation with mental health (r = .265*) as did treatment control (r = .371*). Treatment control was also an important explaining variable of mental health (β = -.22*) **Coping:** personal control has a significant positive relation with problem-focused coping (β = .36**)	**Coping:** Emotional representation correlated negatively with mental health (r = -.469*) and is an explaining variable of mental health (β = -.32**). Emotional representation (β = .23*) significantly explained 8.4% of the variance in scores of venting emotions (F = 6.64)*	Not assessed

Table 4. Continued

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	Identity	Cause	Timeline	Consequences	Control	Emotional representat.	Coherence
Rabin et al. (2004)	Not assessed	Not assessed	**Psychological distress:** Patients reported more anxiety (F=8.18**) and depression (F=8.37**) if they believed that their cancer timeline was chronic or cyclical. **Fear of recurrence:** Patients reported higher fear of recurrence (F=9.69**) if they believed that their cancer timeline was chronic or cyclical.	Not assessed	Not assessed	Not assessed	Not assessed
Corter et al. (2013)	**Fear of recurrence:** Identity perceptions (more symptoms attributed to breast cancer) are significantly related to fear of recurrence (β = .19*)	**Fear of recurrence:** Perceived stress as cause of cancer associated with higher fear of recurrence (mean difference between groups = -2.7*). Lower fear of recurrence in women who reported not knowing the cause of their cancer (mean difference between groups = 4**).	**Fear of recurrence:** Longer timelines for the experience of breast cancer were significantly associated with fear of recurrence (β = .23*)	**Fear of recurrence:** Higher fear of recurrence associated with beliefs in higher consequences of breast cancer (r = .59**)	**Fear of recurrence:** Lower beliefs about treatment control were significantly associated with fear of recurrence (β = -.24**). Beliefs about personal control over cancer recurrence were not associated with fear of recurrence.	**Fear of recurrence:** More negative emotions associated with the diagnosis were significantly associated with fear of recurrence (β = .32**)	**Fear of recurrence:** Higher fear of recurrence is associated with lower coherence (r = -.27**)

Table 4. Continued

	Identity	Cause	Timeline	Consequences	Control	Emot. Repres	Coherence
Duric et al. (2007)	**Changes in health practices:** Identity was the strongest psychosocial predictor associated with judging smaller benefits sufficient to make adjuvant chemotherapy worthwhile (p = 0.01).	Cause was not a significant predictor associated with judging smaller benefits sufficient to make adjuvant chemotherapy worthwhile.	Timeline was not a significant predictor associated with judging smaller benefits sufficient to make adjuvant chemotherapy worthwhile.	**Changes in health practices:** Lower scores for perceived consequences of early breast cancer (p = .04) were associated with judging smaller benefits sufficient to make adjuvant chemotherapy worthwhile.	Control was not a significant predictor associated with judging smaller benefits sufficient to make adjuvant chemotherapy worthwhile.	Emotional representations was not a significant predictor associated with judging smaller benefits sufficient to make adjuvant chemotherapy worthwhile.	Not assessed
Mc Corry et al. (2013)	**Psychological distress:** Cluster 1 (women with cognitions that the illness has a more chronic and cyclical timeline, more severe consequences, more symptoms and have lower personal and treatment control and a less coherent understanding of the illness. Also includes women who endorse causal attributions more strongly, having greater perceptions of emotional, behavioural and externalized causes) women had higher levels of anxiety and depression compared to women in cluster 2 both at diagnosis (β = .418** and β = .405* respectively) and six months post diagnosis (β = -.25** and β = -.36* respectively). The clusters were derived by conducting a two-stage cluster analysis and Ward's clustering method was used to identify the number of clusters. A *K*-mean analysis was then conducted using the number of clusters and the centroids identified by Ward's method. Cluster 2 included women with cognitions that the illness has a less chronic and cyclical timeline, less severe consequences, less symptoms and have greater personal and treatment control and a more coherent understanding of the illness. Also includes women who endorse causal attributions less strongly, having weaker perceptions of emotional, behavioural and externalized causes)	**Psychological distress:** Cluster 1 women had higher levels of anxiety and depression compared to women in cluster 2 both at diagnosis (β = -.418** and β = -.405* respectively) and six months post diagnosis (β = -.25** and β = -.36* respectively).	**Psychological distress:** Cluster 1 women had higher levels of anxiety and depression compared to women in cluster 2 both at diagnosis (β = -.418** and β = -.405* respectively) and six months post diagnosis (β = -.25** and β = -.36* respectively).	**Psychological distress:** Cluster 1 women had higher levels of anxiety and depression compared to women in cluster 2 both at diagnosis (β = -.418** and β = -.405* respectively) and six months post diagnosis (β = -.25** and β = -.36* respectively).	**Psychological distress:** Cluster 1 women had higher levels of anxiety and depression compared to women in cluster 2 both at diagnosis (β = -.418** and β = -.405* respectively) and six months post diagnosis (β = -.25** and β = -.36* respectively).		**Psychological distress:** Cluster 1 women had higher levels of anxiety and depression compared to women in cluster 2 both at diagnosis (β = -.418** and β = -.405* respectively) and six months post diagnosis (β = -.25** and β = -.36* respectively).

Table 4. Continued

	Identity	Cause	Timeline	Consequences	Control	Emotional representat.	Coherence
Iskanarsyah et al. (2013)	**Social and emotional support:** Satisfaction with type and timing of information provided did not explain a significant amount of variance in 'Identity' illness perceptions.	Not assessed	**Social and emotional support:** Satisfaction with type and timing of information provided did not explain a significant amount of variance in 'timeline' illness perceptions.	**Social and emotional support:** Patients who were satisfied with type and timing of information provided had stronger beliefs in personal control over their illness (β = -.30*).	**Social and emotional support:** Patients who were satisfied with type and timing of information provided had stronger beliefs in personal control over their illness (β = -.30*).	**Social and emotional support:** Satisfaction with the amount and content of information explained a significant amount of the variance of emotional representations (β = -.27*).	**Social and emotional support:** Satisfaction with the amount and content of information explained a significant amount of the variance in coherence (β = -.27*).
Croom et al. (2013)	**Quality of life:** Experiencing more cancer related symptoms (t = -6.23**) and perceiving the cancer as central to one's identity (t = -3.03*) was predictive of poorer quality of life	Not assessed	**Changes in health practices:** Greater beliefs about the chronicity of the timeline were significantly associated with a greater number of advanced illness behaviours (r= .30**). **Quality of life:** Greater beliefs in the timeline being cyclical were significantly associated with a poorer quality of life (r= -.37**).	**Changes in health practices:** Participants who reported completing a higher frequency of advanced illness behaviours (e.g. discussing cancer and/or their future with important people or completing an advance directive) perceived their cancer as having more severe consequences (t = 3.19*).	**Quality of life:** No significant associations were found between personal and treatment control and quality of life. **Changes in health practices:** No significant associations were found between personal and treatment control and advanced illness behaviours.	Not assessed	**Changes in health practices:** Participants who reported completing a higher frequency of advanced illness behaviours (e.g. discussing cancer and/or their future with important people or completing an advance directive) perceived their cancer as more understandable (i.e. illness coherence; t =2.49*)

Identity

Evidence for an association between perceived identity (symptoms that the individual believes are associated to the illness) psychosocial factors in female cancer patients is limited. Six studies included in this review measured perceived identity in relation to psychosocial outcomes (Corter et al., 2013; Croom et al., 2013; Duric et al., 2007; Mc Corry et al., 2013; Millar et al., 2005; Rozema, Völlink & Lechner, 2009).

Significant negative relationships between identity and psychological well-being were found in two studies. Millar et al. (2005) found that reporting a greater number of symptoms associated with cancer (i.e. identity) was a predictor of distress at three, six and twelve months following breast surgery. Furthermore, Rozema et al. (2009) found that identity correlated negatively with mental health outcomes as measured on the RAND-36. The same study also found identity to be related to cognitive and behavioural avoidance as a coping strategy. One study reported that more cancer-related symptoms are significantly related to fear of recurrence (Corter et al., 2013).

Only one study explored the association between quality of life and identity (Croom et al., 2013) reporting that experiencing more cancer-related symptoms and perceiving the cancer as central to one's identity was predictive of poorer quality of life.

Illness identity was found to be associated with changes in health practices in one study; higher identity scores (i.e. attributed common, non-specific somatic symptoms to their breast cancer diagnosis or adjuvant chemotherapy) were associated with perceived larger benefits necessary to make adjuvant chemotherapy worthwhile. (Duric et al., 2007) These findings suggest that patients' preferences for treatment are formed by an integration of factors, including individual beliefs about the illness (identity).

Timeline (chronicity and cyclical)

Timeline includes two components: chronic timeline and cyclical timeline. Chronic timeline refers to beliefs about the relative chronicity of the illness whilst cyclical timeline refers to beliefs about fluctuations in the symptoms and the temporal variability of the illness (this subscale is particularly useful when working with patients whose illness cannot be adequately captured on a simple acute/chronic dimension such as skin cancers where the condition could be experienced as a stable disease or could be experienced as a timely variation of disease severity).

Seven studies included in this review measured timeline beliefs (Corter et al. 2013; Croom et al. 2013; Gould et al., 2010; Mc Corry et al., 2013; Millar et al., 2005; Rabin et al. 2004; Rozema et al., 2009). All of these studies explored the relationship between timeline beliefs and psychological well-being. Millar et al. (2005) identified that the shorter perceived timeline of the illness, the greater the distress at 6 and 12 months following breast surgery, which might imply pessimism about survival especially in the first 12 months following treatment. Additionally, acute/chronic timeline was found to correlate with mental health outcomes (Rozema et al., 2009). Greater beliefs about the chronicity of the timeline were found to be significantly associated with a greater number of advanced illness behaviours (e.g. participation in cancer-specific activities, preparation for medical decision making, and end of life planning) and greater beliefs in the timeline being cyclical were significantly associated with a poorer quality of life (Croom et al. 2013). Furthermore, patients reported more anxiety and depression if they believed that their cancer timeline was chronic or cyclical (Rabin et al., 2004) and perceptions of a cyclical timeline were related to higher scores on a measure of mood disturbance (Gould et al., 2010).

Associations between timeline perceptions and fear of recurrence were explored in two studies. Patients reported a greater fear of recurrence if they believed that their cancer timeline was chronic or cyclical (Rabin et al., 2004) and if they perceived the timelines for the experience of breast cancer to be longer (Corter et al., 2013).

Perceptions of a chronic timeline had a strong negative correlation with cognitive and behavioural avoidance as a coping strategy in women with breast cancer (Rozema et al., 2009). Denial and disengagement coping strategies were found to mediate paths between perceptions of a cyclical timeline and higher mood disturbance scores in women recently diagnosed with gynaecological cancer (with positive associations between the three variables in the mediation path) (Gould et al., 2010).

Consequences

Twelve studies included a measure of patients' perceptions about consequences of the illness, although the methods used to assess this dimension varied across studies (Awasthi et al., 2006; Awasthi et al., 2010; Corter et al. 2013; Costanzo et al., 2011; Croom et al. 2013; Duric et al., 2007; Gould et al., 2010; Jorgensen et al., 2009; Mc Corry et al., 2013; Rozema et al., 2009; Silva et al., 2012).

Perceptions about consequences in relation to psychological distress were investigated in three studies. Silva et al. (2012) found that negative perceptions of consequences were significantly associated with higher emotional distress (specifically, depression and anxiety). In addition, Gould et al. (2010) found that the greater the perceived consequences of cancer, the greater the score on a measure of mood disturbance in gynaecological cancer patients; and Rozema el al. (2009) identified a significant negative correlation between illness perception consequences and mental health outcome measures.

Silva et al. (2012) explored the relationship between posttraumatic growth and perceived illness consequences in women with breast cancer. They found that posttraumatic growth moderated the relationships between negative perceptions of the consequences of breast cancer and quality of life, acting as a stress-buffering mechanism. Among women who perceived breast cancer as having more negative consequences, higher posttraumatic growth buffered this negative perceived impact on psychological and social quality of life ($p<0.01$) and also on depression ($p<0.06$). This effect was not found for physical QOL and anxiety.

The relationship between fear of recurrence and consequences of breast cancer was explored by only one study; it was reported that beliefs in more severe consequences of breast cancer are associated with a greater fear of recurrence (Corter et al., 2013).

Perceptions about consequences of cancer were explored in relation to quality of life (in two studies) identifying that higher scores on quality of life were associated with a perception of less severe consequences in breast cancer patients (Jorgensen et al., 2009). In addition, Silva et al.'s (2012) study identified a significant association between negative perceptions of consequences and impaired physical and psychological quality of life in breast cancer patients.

Relationships between illness perception consequences and changes in health practices were found across three studies. Costanzo et al. (2011) found that women who perceived more severe consequences of their breast cancer at three weeks post-treatment were more likely to report increasing the frequency with which they avoided stress by three months post-treatment. Furthermore, in a study aimed at exploring women's preferences with regards to receiving adjuvant chemotherapy treatment in breast cancer, the authors identified that lower scores for perceived consequences of early breast cancer were associated with judging smaller

benefits sufficient to make adjuvant chemotherapy worthwhile (Duric et al., 2007). Additionally, Croom et al.'s (2013) study showed that participants who reported completing a higher frequency of advanced illness behaviours (e.g. participation in cancer-specific activities, preparation for medical decision making, and end of life planning) perceived their cancer as having more severe consequences.

Two studies carried out in India explored social and emotional support in relation to perceptions about the consequences of cancer in a sample of women with a diagnosis of cancer of the cervix. A greater level of social support was related to less severe perceived consequences (Awasthi et al., 2006). Exploration of inter-relationships between illness perceptions highlighted that practical support as well as doctor-control and supernatural causes accounted for approximately 49% of the variance in score on the interpersonal consequences measure. Practical support accounted for approximately 40% of the variance in scores. Overall support, "doctor" control and supernatural causes explained approximately 41% of the variance in scores on psychological consequences (Awasthi et al., 2010). It may be important however to acknowledge that these studies included cervix cancer patients recruited from urban and rural areas in India and the sample included educated and uneducated participants. The generalisability of the findings may therefore be limited by factors such as education and location associated with the sample.

Cause

Causal illness perceptions can be categorised into four main groups: psychological attributions (e.g., stress or worry), risk factor attributions (e.g., hereditary factors), immunity attributions (e.g., a germ or a virus) and chance attributions (e.g., chance or bad luck) (Moss-Morris et al., 2002).

Seven studies included in this review explored causal illness perceptions, although the methods used to assess this dimension varied across studies (Awasthi et al., 2010; Cameron et al., 2005; Corter et al., 2013; Costanzo et al., 2011; Jorgensen et al., 2009; Mc Corry et al., 2013; Rozema et al. 2009).

The relationship between causal beliefs and psychological well-being was explored in six studies. Jorgensen et al. (2009) found that causal beliefs of stress or worry explained 22% of variance in general distress whereby higher levels of general distress were associated with a stronger belief that stress or worry caused the illness. Furthermore, Cameron et al., (2005) found that causal beliefs of altered immunity and stress positively correlated with each other. Perceived stress as a cause of cancer was also associated with higher fear of recurrence whilst a lower fear of recurrence was expressed in women who reported not knowing the cause of their cancer (Corter et al., 2013).

A study exploring coping behaviours in relation to causal beliefs found that psychological beliefs about cause were significantly related to behavioural avoidance as a coping strategy (Rozema et al. 2009) although these results are not discussed in depth in the paper.

The relationship between social and emotional support and causal beliefs of cancer was investigated in two studies. Cameron et al. (2005) identified that altered immunity causal beliefs and illness distress were associated with a higher propensity to participate in a support group. Additionally, Awasthi et al. (2010) found that beliefs about individual, psychosocial and supernatural causes negatively correlated with emotional, informational, social companionship and practical support (i.e. women who received less support believed more strongly in these causes of cancer).

Costanzo et al.'s (2011) study was the only one to look at causal beliefs of cancer in relation to changes in health practices. Causal beliefs linked to diet were associated with an increase in consumption of fruits and vegetables and decreased fat intake. Causal beliefs linked to lack of exercise were associated with increased physical activity. Causal beliefs linked to stress or worry were associated with avoidance of stressful situations at three weeks and three months post-treatment.

Control

The IPQ includes a single dimension of control/cure whilst the IPQ-R distinguishes between the belief in one's own ability to control illness (personal control) and the belief in the efficacy of the treatment (treatment control).

Six studies included in this review measured perceived control in relation to psychosocial factors (Awasthi et al., 2006; Awasthi et al., 2010; Corter et al. 2013; Costanzo et al., 2011; Gould et al., 2010; Hanselmans et al., 2009; Jorgensen et al., 2009; Rozema et al., 2009).

Psychological well-being outcomes were explored in relation to perceived control in five studies. Hanselmans et al. (2009) found that women with a strong sense of personal control over life reported less anxiety two months after the end of treatment for breast cancer, controlling for baseline. In addition, Gould et al. (2010) found that personal control and treatment control correlated with mood disturbance (the greater the perceptions of control, the lower the scores on the mood disturbance scale). Furthermore, Rozema et al. (2009) found that greater treatment control was positively associated with better mental well-being and was also an important variable in explaining mental health outcomes. Greater personal control was also found to have a significant positive relationship with problem-focused coping (Rozema et al., 2009). A study that looked at the relationship between treatment control and fear of

recurrence found that lower beliefs about treatment control were significantly associated with fear of recurrence (Corter et al., 2013).

Jorgensen et al.'s (2009) study was the only one to look at the relationship between control beliefs and quality of life; higher quality of life was found to be associated with a perception of greater treatment control beliefs. These results are no longer significant however, once controlled for demographic variables.

The relationship between control perceptions and social and emotional support was looked at in two studies; Awasthi et al. (2006) identified that patients who scored higher on the social support measure held stronger beliefs in "self" and "doctor" for illness control than those who scored lower on the social support measure. Differences between these groups were significant with respect to self and doctor. Greater "self" control correlated with less informational and social companionship support and positively correlated with practical support. "Doctor" control was positively correlated with emotional, informational, social companionship and practical support (Awasthi et al., 2010).

Emotional representations

Emotional representations relate to patients' emotional responses to their illness. Only three studies in this review explored the relationship between emotional representations and psychosocial outcomes (Corter et al., 2013; Rozema et al., 2009; Iskanarsyah et al., 2013).

Two studies looked at emotional representations in relation to psychological well-being. Rozema et al. (2009) found that experiencing breast cancer as an illness with major emotional consequences was related to a lower use of problem-focused coping. Furthermore, the study showed that a greater score on the emotional representations subscale only had a significant

positive correlation with the emotion-focused coping strategy of "venting" (and not with the other emotion focused coping strategies e.g. behavioural avoidant coping, seeking social support, and cognitive avoidant coping). Emotional representations significantly explained 8.4% of the scores of venting emotions. Negative emotional consequences of cancer were significantly associated with negative mental health outcomes. Additionally, one study looked at the association between emotional representations in relation to fear of recurrence. Corter et al. (2013) found that negative emotions associated with the diagnosis were significantly associated with fear of recurrence.

Illness coherence

The coherence subscale of the IPQ-R has the function of assessing the extent to which a patient feels that they understand their illness, or if it appears mysterious or incomprehensible.

Only five studies in this review explored the relationship between illness coherence and psychosocial outcomes (Corter et al., 2013; Croom et al. 2013; Gould et al., 2010; Mc Corry et al., 2013; Iskanarsyah et al., 2013).

Two studies were interested in psychological well-being outcomes in relation to illness perceptions; Gould et al. (2010) found that denial and disengagement coping styles mediate paths between perceptions of low coherence and higher mood disturbance. Additionally, Corter et al. (2013) identified that higher fear of recurrence is associated with lower coherence.

Croom et al. (2013) found that participants who reported completing a higher frequency of advanced illness behaviours (e.g. participation in cancer-specific activities, preparation for medical decision making, and end of life planning) perceived their cancer as more

understandable. In addition to this, Iskanarsyah et al. (2013) found that patients who were satisfied with the type and timing of information provided to them reported that they felt they had a better understanding of their illness (greater illness coherence).

In addition to the above studies, Mc Corry et al. (2013) employed cluster analysis to investigate the associations between psychological distress and illness perceptions in female breast cancer patients. Cluster 1 included women with cognitions that the illness had a more chronic and cyclical timeline, more severe consequences, more symptoms and had lower personal and treatment control and a less coherent understanding of the illness. Cluster 1 also included women who endorsed causal attributions more strongly, having greater perceptions of emotional, behavioural and externalized causes. Cluster analysis revealed that women in cluster 1 had higher levels of anxiety and depression compared to women in cluster 2 (cluster 2 included women with cognitions that the illness has a less chronic and cyclical timeline, less severe consequences, less symptoms and have greater personal and treatment control and a more coherent understanding of the illness. Also includes women who endorse causal attributions less strongly, having weaker perceptions of emotional, behavioural and externalized causes) both at diagnosis and six months post diagnosis.

DISCUSSION

The aim of this review was that of exploring the relationship between illness perceptions and psychosocial factors in female cancer patients. Gender differences in how men and women perceive their illness lead to different and unique needs of women compared to men coping with similar stressors (Vazquez, Gibson, & Kustra, 2007). Furthermore, the process of developing illness perceptions cannot be seen in isolation from the social differences in gender that are so prevalent in our society (Friedman, 2011). As far as we know, no previous literature review has explored these relationships. A thorough search and data extraction strategy was used, followed by a quality assessment for each paper.

A pattern of relationships between negative illness perceptions and poor psychosocial outcomes was evident across studies (Millar et al. 2005; Jorgensen et al., 2009; Cameron et al., 2005; Silva et al. 2012; Henselmans et al. 2009; Gould et al. 2010; Rozema et al., 2009; Rabin et al. 2004; Corter et al., 2013; Mc Corry et al., 2013; Croom et al., 2013). Psychological distress was the construct most often measured in the studies and it was also the construct most frequently significantly associated with illness perceptions (Cameron et al., 2005; Gould et al. 2010; Henselmans et al. 2009; Jorgensen et al., 2009; Mc Corry et al., 2013; Millar et al. 2005; Rozema et al., 2009; Silva et al. 2012).

Psychological distress was found to be associated with the full range of illness perceptions. Negative identity and timeline perceptions were predictive of distress in a longitudinal study (Millar et al., 2005) and negative perceptions of consequences were associated with greater emotional distress (Silva et al., 2012, Gould et al., 2010; Rozema et al., 2009). Higher levels of distress were also associated with stronger beliefs in stress or worry as cause of the cancer (Jorgensen et al., 2009; Cameron et al., 2006). The association between psychological distress

and the full range of illness perceptions in female cancer patients is consistent with research which has found moderate to strong relationships between illness perceptions and psychological well-being in a number of illnesses and across male and female populations (Hagger & Orbell, 2003; Kaptein et al., 2003).

In the present review the 'consequences' illness perception was the illness perception most commonly associated with psychosocial outcomes (including quality of life, changes in health practices, psychological distress, posttraumatic growth, fear of recurrence and social and emotional support). Perceptions of less severe consequences of the illness were associated with better quality of life (Jorgensen et al., 2009) and better psychological well-being (Rozema et al., 2009; Silva et al., 2012; Gould et al., 2010; Corter et al., 2013; Mc Corry, 2013). More severe perceived consequences were associated with changes in health practices (i.e. completing more advanced illness behaviours) (Croom et al., 2013). This association highlights the important relationship between the way in which a woman perceives the consequences of her illness and her psychological well-being.

In line with research carried out in other physical health populations (Hagger & Orbell, 2003; Foxwell et al., 2013; Parfeni et al., 2013), the present review found that, in female cancer patients, perceiving greater negative consequences appeared to have the strongest relationship with poorer quality of life and elevated psychological distress. These results fit with psychological theories, which describe how people's perceptions of, or thoughts about, situations influence their emotional, behavioural (and often physiological) reactions (e.g. Beck et al., 1979; Beck, 1995). So it is not surprising that women's negative beliefs about the consequences of their cancer negatively affect their psychological well-being and their quality of life.

The control and timeline illness perceptions were under-explored in relation to QoL in female cancer patients in the present review, with only one study reporting higher quality of life associated with higher treatment control beliefs (Jorgensen et al., 2009). Research in other physical health populations suggests that a lesser belief in a chronic timeline is associated with greater QoL (Scharloo et al., 2007; Alsén, Brink, Persson, Brändström & Karlson, 2010). From the analytic approach taken and from the data extracted from the papers it appears that the associations between identity, cause, emotional representations and coherence perceptions and psychosocial outcomes were the least frequently explored illness perception domains in female cancer patients.

In summary, this review illustrates a complex picture of a multitude of factors related to psychosocial well-being and the domains of the self-regulatory model and the possible inter-relationships between these factors. Overall, the 16 studies reviewed have presented mixed results; the analytic approach taken and the data extracted from the papers shows that certain dimensions of illness perceptions appear to have been studied more in relation to psychosocial outcomes than others (e.g. perceived consequences and control). The reason for which dimensions of illness perceptions may have been studied more than others may depend partly on the use of different questionnaires across the studies; studies in which the IPQ was used may have included only the four scales ‘identity’, ‘control’, timeline’ and ‘consequences’ and not the ‘cause’ dimension. Additionally, some studies may have chosen to focus specifically on one illness perception dimension (e.g. Henselmans et al., 2009; Rabin et al. 2004; Silva et al; 2012). Further studies looking at psychosocial outcomes across all dimensions of the IPQ-R (in particular emotional representation and coherence) are warranted.

Additionally, the perceived consequences and control dimensions of the illness perception questionnaire are more consistently and strongly associated with some of the psychosocial

outcomes than others (e.g. psychological distress). Further studies investigating the relationship between illness perceptions and psychosocial outcomes such as 'social and emotional support', 'changes in health practices', 'post-traumatic growth' and 'coping' are warranted. From the analytic approach taken and from the summary of findings illustrated in Table 4 one can conclude that there was a consistent finding across the female cancer groups of worsening illness perceptions, poorer quality of life and elevated psychological distress (Jorgensen et al. 2009; Millar et al., 2005; Cameron et al., 2005; Silva et al., 2012; Henselmans et al., 2009; Gould et al., 2010; Rozema et al., 2009; Rabin et al., 2004; Mc Corry et al., 2013; Croom et al., 2013).

Overall the evidence from the current review suggests that women who experience cognitions of a more chronic and cyclical nature, more severe consequences, more symptoms and have lower personal and treatment control and a less coherent understanding of the illness tend to experience poorer psychosocial outcomes. Negative thoughts can lead women to experience a variety of feelings including sadness, anger or anxiety; these in turn can have an impact on a women's bodily sensations (e.g. feeling tense, tired or lethargic) and can influence her behaviours (e.g. becoming isolated). These in turn can lead to more negative thoughts, which in turn lead to feelings of low mood. This is a vicious cycle in which thoughts, feelings, physical sensations and behaviours influence one another and maintain the problem over time.

Limitations

There are a number of limitations to the current review. Firstly, the diversity of the participants taking part in the studies; these included females with different cancer diagnoses (breast, cervix, gynaecological and lung) and at different stages of their cancer journey (some with non-metastatic cancer and receiving curative treatment and some at the palliative stage

of care). This variability makes it difficult to generalise the findings as illness perceptions are likely to change in relation to type of illness and stage of illness. Additionally, significant cultural diversity was apparent across the studies. The studies in the present review originated from the UK, USA, Denmark, Portugal, Australia, the Netherlands, New Zealand, Indonesia and India. Illness perceptions in some of these cultures may be different to others worldwide. For example, Awasthi et al. (2006) found that rural and uneducated women in India held strong beliefs in the supernatural causes of illness. These findings reflect the Hindu world-view and religious philosophy of women, and illustrate a fundamental difference between western and Indian belief systems (Awasthi et al., 2006*).*

A number of different measures were used to assess illness perceptions and psychosocial outcomes across the different studies. Two studies used self-generated questionnaires to measure illness perceptions (Awasthi et al., 2006; Awasthi et al., 2010), which may have been measuring slightly different concepts to those defined by the self-regulatory model. Drawing conclusions may be difficult if the concepts differ between studies, however the authors did not explain the reason for which the measure was developed (for example in order to be culturally appropriate).

Another limitation of the studies is that of self-selecting sample bias in many of the studies (Jorgensen et al., 2009; Cameron et al., 2005; Henselmans et al., 2009; Gould et al., 2010; Rozema et al., 2009; McCorry et al., 2013) i.e. the reasons for which some patients chose not to participate may have been due to distress or physical health problems. Furthermore, small sample sizes and low power were limitations in some of the studies (Costanzo et al, 2011; Henselmans et al., 2009; Duric et al., 2007; Iskandarsyah et al., 2013; Awasthi et al., 2006; Awasthi et al., 2010; Jorgensen et al., 2009; Henselmans et al., 2009). In addition, the cross-sectional design of many of the studies limits the understanding of dynamic processes and

possible causal relationships (Silva et al., 2012; Gould et al., 2010; Corter et al., 2013; Iskandarsyah et al., 2013).

The quality checklist of 11 items (Kmet, Lee & Cook, 2004) used to assess the quality of the studies included in the review presented a number of issues, which add to the limitations of the review. The checklist has a low threshold for quality; for example the quality of two studies (Awasthi et al., 2006; Awasthi et al., 2010) seemed lower than the rest even though they received a 'moderate' quality rating. The method and participant recruitment did not appear to be described in sufficient detail. The outcome measures were not sufficiently well defined, the sample sizes were quite small and neither of these studies reported any limitations. This may highlight a weakness in the quality rating measure in assessing poorer quality studies (Kmet et al., 2004). In addition to this, the quality criteria are quite vague (e.g. 'Sample size appropriate?' or 'Controlled for confounding?'), which reduces the reliability of the measure. Another limitation linked to the use of this framework is that several of the criteria in the checklist were not applicable to the studies (e.g. 'If an intervention or random allocation was possible, was it described?'; 'If interventional and blinding of subjects was possible, was it reported?'; 'Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?').

Clinical implications

A number of studies included in this review highlight the importance of developing interventions designed to change inaccurate and negative illness perceptions in order to improve psychosocial outcomes (Rozema et al., 2009; Iskandarsyah et al., 2013; Costanzo et al., 2011). Assessment of illness perceptions can be carried out quickly and easily and can be helpful in providing guidance to health care planning (for example by assessing whether a

patient's belief about the ability of their treatment to control their illness or by assessing what they believe the consequences of their illness to be) and can potentially support the identification of patients at greater risk of negative psychosocial outcomes and mental health problems.

Previously tested psychological hospital-based interventions designed to change negative illness perceptions have been found to mediate treatment related improvements and improve psychological well-being (Chilcot & Moss-Morris, 2013; Traeger et al., 2013; Petrie et al., 2002). For example positive change in illness perceptions following intervention was found to mediate the treatment effect on improved irritable bowel syndrome symptom severity and social adjustment six months later (Chilcot & Moss-Morris, 2013). Intervention programmes using the illness perception model have been run with participants experiencing different physical illnesses (Hale et al., 2007). Interventions using cognitive-behavioural techniques have been found to lead to improvements in participants' illness perceptions of treatment control, reductions in perceptions of the negative emotional impact of the condition and reductions in stress levels in Systemic Lupus Erythematosus (Goodman et al., 2005). Additionally, interventions have been shown to change/improve illness perceptions related to timeline chronicity, severity of consequences and poor perceived control as well as improve physical symptomatology in patients who have experienced a myocardial infarct (Petrie et al., 2002).

Adequate and sufficient information about which symptoms are related to the illness and which consequences to expect in social, financial and emotional functioning is also important (Rozema et al., 2009) since satisfaction with information provided has been associated with better outcomes, including more positive illness perceptions (Iskandarsyah et al., 2013).

Recommendations for future research

The present review highlights a complex picture of inter-relationships between domains of the self-regulatory model and a number of psychosocial outcomes. These are all important factors that need to be investigated further within this population. Future research is required, including larger samples since some studies with small sample sizes were identified in the quality review. Furthermore, further research using prospective and longitudinal designs measuring the dimensions of the self-regulatory model across two or more points in time would be helpful as these would give some insight into whether and how illness perceptions change over time. Additionally, further studies investigating the relationship between illness perceptions and psychosocial outcomes such as 'social and emotional support', 'changes in health practices', 'post-traumatic growth' and 'coping' are warranted as this review highlighted the scarcity of studies investigating these psychosocial outcomes.

The present review also highlighted a discrepancy between domains of the self-regulatory model that have received more attention (identity, cause, consequences, timeline and control) and those that appear to attract less interest (emotional representations and coherence). It is worth acknowledging however that the emotional representations and coherence subscales are newer inclusions in the IPQ-R. However, they might be worth further investigation.

Conclusion

Significant associations exist between illness perceptions and psychosocial outcomes in female cancer patients. A pattern of relationships between more negative illness perceptions and poorer psychosocial outcomes is evident across studies. A pattern of relationships between negative illness perceptions and poor psychosocial outcomes was evident across studies (Millar et al. 2005; Jorgensen et al., 2009; Cameron et al., 2005; Silva et al. 2012;

Henselmans et al. 2009; Gould et al. 2010; Rozema et al., 2009; Rabin et al. 2004; Corter et al., 2013; Mc Corry et al., 2013; Croom et al., 2013). Psychological distress was the construct most often measured in the studies and it was also the construct most frequently significantly associated with illness perceptions (Cameron et al., 2005; Gould et al. 2010; Henselmans et al. 2009; Jorgensen et al., 2009; Mc Corry et al., 2013; Millar et al. 2005; Rozema et al., 2009; Silva et al. 2012). The literature in this field however does not currently allow for a clear and in-depth understanding of the specific psychosocial factors associated with each individual domain of the self-regulatory model in female cancer patients.

Further research is necessary in order to gain a full and in-depth understanding of the psychosocial factors related to each domain of the self-regulatory model in female cancer patients. This will be helpful in the identification process of ‘at-risk groups’ and in the further development of interventions targeted at generating less negative and more realistic illness perceptions.

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CHAPTER TWO

EMPIRICAL PAPER

ILLNESS PERCEPTIONS, RESILIENCE AND PSYCHOLOGICAL WELL-BEING IN CANCER SURVIVORS

ABSTRACT

Objective: This study explored the relationship between illness perceptions, resilience and psychological well-being in cancer survivors. It was hypothesised that those with lower resilience and more negative illness perceptions would experience a poorer quality of life (QoL) and poorer psychological well-being.

Method: A total of 251 cancer survivors (139 male, 112 female) took part in the study. Outcome measures completed by participants included measures of illness perceptions, resilience, QoL and psychological well-being.

Results: Age, treatment type, components of the self-regulation model and resilience, explained 16.2% of the variability in QoL. The strongest predictors of QoL were resilience and perceived consequences, followed by perceived treatment control. Also, age, treatment type, components of the self-regulation model and resilience, explained 24.3% of the variability in psychosymptomatology. The strongest predictors of psychological distress were resilience, then age and perceived consequences, followed by emotional representations and treatment control.

Conclusions: Results are in line with previous studies, showing that there are significant relationships between resilience, illness perceptions and psychological well-being in cancer survivors. Patients may benefit from psychological interventions to address negative illness perceptions and increase resilience. Further research is needed to confirm and expand on these findings.

INTRODUCTION

Over 331,000 people were diagnosed with cancer in 2011 in the UK (Cancer Research UK, 2014). Improvements in early detection and treatment of different types of cancer have substantially improved over the past two decades leading to cancer survival rates in the UK doubling in the last 40 years (Cancer Research UK, 2014). Early detection and an ageing population have however led to incidence rates rising (DeSantis, Ma, Bryan & Jemal, 2014) with the number of cancer survivors increasing by ~3% each year (Maddams, Brewster, Gavin, Steward, Elliott, Utley & Møller, 2009). In 2008 there were estimated to be two million cancer survivors in the UK (Maddams et al., 2009) and this number is estimated to increase to four million by 2030 (Maddams et al., 2009).

A cancer survivor is someone who has had a diagnosis of cancer in the past, and may or may not have an active disease, or is living with progressive disease but is not terminally ill (Macmillan Cancer Support, 2011). The NHS Cancer Reform Strategy (Department of Health, 2007) states the importance of provision of social and psychological assistance to cancer survivors in order to resume 'as normal a life as they can'. Cancer survivors often find it difficult to manage the symptoms of cancer and the side effects of treatment, which have an impact on their quality of life (QoL) (DeSantis et al., 2014) including poorer social and psychological functioning (Badr & Taylor, 2008; Costanzo, Lutgendorf, Mattes, Trehan, Robinson, Tewfik & Roman, 2007; Montazeri, 2008).

Receiving a diagnosis of a serious illness does not always lead to adverse mental health outcomes in all individuals. There is a great variability in response to the diagnosis, with some individuals experiencing higher levels of distress, whilst others respond in a more resilient way, with less psychological distress (Moskowitz, 2010). Studies have found that up

to 58% of cancer patients experience depressive symptoms and up to 38% have major depression (Massie, 2004; Williams & Dale, 2006). Resilience is seen as the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma (Windle, 2011). It is a dynamic process that has been defined as an outcome of successful adaptation to adversity (Zautra, Hall & Murray, 2008) and can be seen as a combination of abilities that interact to allow an individual to 'bounce back', cope and function in spite of significant stress or adversity (Tusaie & Dyer, 2004).

In the past two decades interest in the concept of resilience has increased due to dissatisfaction with models that focus on patient psychopathology and illness, and there has been a move towards models that focus on patient strengths (Windle, 2011). These deficit models tend to define patients in negative terms, focusing on classical risk factors e.g. health behaviour, lifestyle and low income without acknowledging positive factors (Harrison, Ziglio, Levin & Morgan, 2004). This has led to an increased interest in what protects health in the face of adversity and promotes coping abilities of individuals and less dependency on professional services (Harrison et al. 2004; Morgan & Ziglio, 2007). Resilience has also become more central to policy and practice whereby there is an increasing awareness of the importance of the concept in policies and programmes to support improved mental health for the whole population (Friedli, 2009). For example, in the UK reports have been recently published setting out the types of services, resources and infrastructure needed in order to support resilient communities and for mental well-being to improve (Mental Health Strategic Partnership, 2013).

A systematic review carried out by Stewart and Yuen (2011) highlighted a number of psychological factors associated with resilience in patients with a chronic physical illness such as self-efficacy, self-esteem, internal locus of control, optimism, mastery, hardiness,

hope, self-empowerment, acceptance of illness and determination. Given the contribution of genetic, environmental, coping factors and past experiences to resilience, regardless of the type of adversity encountered, these results were unsurprising (Stewart & Yuen, 2011). This review also found that resilience was associated with factors directly salient to physical illness such as self-care, adherence to treatment and exercise regimes, and perception of pain (Stewart & Yuen, 2011).

Cancer patients with high resilience have been found to be less dependent on psychosocial support to manage their stressful conditions relative to those with low resilience (Brix, Schleussner, Füller, Roehrig, Wendt & Strauss et al., 2008). Also, resilience has been found to predict patients' fatigue at least in the early stages of radiotherapy (Strauss et al., 2007) and has been found to be positively related to QoL in cancer patients (Manne et al., 2014; Armando, da Motta, Pinto, Matiello, Da Silva & Ferreira Filho, 2010).

Illness perceptions, also known as illness representations, are believed to have an important role in guiding the decisions people make around managing their treatment regimens and to influence their coping strategies and, in turn, have an impact on the individual's illness outcomes and emotional well-being (Leventhal, Halm, Horowitz, Leventhal & Ozakinci, 2005). A number of studies have shown that people's cognitive representations of illness are made up of a cluster of perceptions that influence behavioural and emotional responses to the diagnosis and the treatment of the illness (Leventhal, Meyer & Nerenz, 1980; Traeger et al., 2009). Leventhal's Self-regulation Model describes how an individual develops an understanding that they are unwell (constructing cognitive representations about the illness or disease) and what they do to cope and how they respond to their illness.

Illness perceptions can be categorised into five main domains: identity (the label given to the illness), cause (beliefs around the perceived biological, emotional, psychological and/or environmental cause of the illness), timeline (beliefs about the course/duration of the illness), consequences (the consequences of the illness physically, socially and psychologically), curability/controllability (beliefs about whether the condition can be cured or kept under control). More recently, two further dimensions have been added the model (coherence and emotional representations) and the cure/control dimension has been separated into two dimensions (treatment control and personal control) (Moss-Morris et al., 2002). Emotional representation refers to emotional responses generated by the illness and illness coherence refers to the extent to which patients feel they have a clear understanding of the illness (Moss-Morris et al., 2002).

Research in recent years has shown that there are strong relationships between illness perception domains and physical and psychological well-being (Cameron & Moss-Morris, 2004; Dorrian, Dempster & Adair, 1999). Meta-analyses and reviews including patients with different illnesses (e.g. cancer, diabetes, irritable bowel syndrome, chronic fatigue syndrome) have found significant relationships between positive and helpful beliefs and an individual's 'identity' illness perceptions (the label or name given to the condition and the statements regarding beliefs about what symptoms arise from the condition), their belief in the controllability of their illness (personal control) and their belief in the appropriateness and effectiveness of the treatment (treatment control) (Hagger & Orbell, 2003; Hampson, 1997; McSharry, Moss-Morris, & Kendrick, 2011). Conversely, more negative illness perceptions (such as emotional representations, identity, consequences and timeline) and were related to more maladaptive outcomes (e.g. poorer social and role functioning and psychological distress) (Hagger & Orbell, 2003; Hampson, 1997; McSharry et al., 2011).

Furthermore, according to Hagger and Orbell's (2003) meta-analytic review of patients across a number of physical health populations, lower perceived consequences and a weaker illness identity have been associated with adaptive psychological outcomes including social, physical and psychological well-being. Furthermore, more negative illness perceptions have been found to predict poorer psychological well-being in men receiving treatment for prostate cancer, particularly among men experiencing greater life stress (Traeger et al., 2009). Given that negative and unhelpful cognitions are known to be associated with the development and maintenance of psychological morbidity (e.g. anxiety and depression) (Beck & Alford, 2009), it is important to evaluate and investigate further the relationship between illness perceptions and psychosocial outcomes in patients with a cancer diagnosis.

There is a 'knowledge gap' in the research around the relationship between resilience and illness perceptions in cancer survivors. Several research studies have investigated the impact of resilience on the psychological wellbeing and the quality of life of cancer survivors (e.g. Armando et al., 2010; Brix et al., 2008; Manne et al., 2014) and many studies have focused on the relationship between illness perceptions and psychological wellbeing and quality of life in cancer survivors (e.g. Traeger et al., 2009; Hagger & Orbell, 2003; Hampson, 1997; McSharry et al., 2011). To our knowledge however, no studies have looked at the relationship between resilience and illness perceptions in cancer survivors and how they impact on psychological well-being and quality of life. This study therefore aims to investigate the relationship between illness perceptions, resilience, QoL and psychological well-being in cancer survivors.

Given that past research shows that negative illness perceptions have been related to maladaptive outcomes including poorer social and role functioning and psychological distress (Hagger & Orbell, 2003; Hampson, 1997; McSharry et al., 2011), it was hypothesised that

more negative illness perceptions would be associated with poorer QoL and poorer psychological well-being.

Secondly, it was hypothesised that resilience would be associated with more positive illness perceptions; resilience was hypothesised to be associated with perceptions of greater controllability of cancer, a more coherent perception of cancer, perceptions of less negative consequences, perceptions of a less chronic/acute timeline and perceptions of cancer being less emotionally loaded. This stems from the definition of resilience as the capacity of individuals to successfully maintain or regain their mental health in the face of significant adversity or risk (Stewart & Yuen, 2011), and it is believed that this would lead to less more realistic and less pessimistic perceptions of the illness. On the other hand, illness perceptions about 'identity' (the label or name given to the condition and the statements regarding beliefs about what symptoms arise from the condition) and 'cause' (beliefs about the cause of the illness) were not believed to be associated with resilience as they could be seen as 'more objective constructs' and would therefore not vary as much between more resilient and less resilient individuals.

Thirdly, it was hypothesised that people with greater resilience would not respond as adversely to negative illness perceptions compared to those with lower resilience. This was hypothesised since negative illness perceptions may have less of an impact on quality of life and psychological well-being in more resilient people (i.e. in those who have a greater capacity to maintain competent functioning in the face of major life stressors, surmount adversity and meet challenges). Receiving a diagnosis of cancer and receiving cancer treatment could lead men and women to cope with different stressful events, such as the lack of personal autonomy, physical illness and disability, and could have a significant impact on work and relationships. It could therefore be hypothesised that greater resilience and more

positive consequences, control and emotional representations illness perceptions would significantly predict better QoL and psychological well-being in cancer survivors.

This research could have significant clinical implications, not only in terms of identifying cancer survivors who may be more vulnerable to psychological distress, but also in terms of informing the development of clinical interventions aimed at improving patients' psychological well-being by targeting unrealistic or negative illness perceptions, correcting unhelpful beliefs, enhancing perceptions of control and promoting resilience.

METHOD

Participants

Participants were identified through a clinical database at the Cancer Centre at University Hospital Birmingham. Five hundred and fifty-seven individuals were invited to take part in the study. Of those, 256 participants chose to take part, resulting in a 45.9% response rate. Forty-nine individuals sent the questionnaire back to record their wish not to participate but did not record a reason. Five individuals declined participation stating that they felt too physically unwell to take part in the study. The remaining 247 individuals did not return the questionnaire. Five participants' data were excluded due to missing data. Four breast cancer patients were male. These scores were excluded from the analyses in order to maintain the gender specificity across the prostate and breast cancer groups. Two hundred and forty-seven participants were included in the final analyses (135 male, 112 female).

Ethical approval was granted through the Solihull Research Ethics Committee (Reference number 13/WM/0079) and the Research and Development Office at University Hospital Birmingham (see Appendix B). The West Midlands Cancer Intelligence Unit (WMCIU) reviewed lists of potential participants' information before questionnaires were posted to participants. This was to ensure that patient information was correct and that participants had not passed away. Patient data was collected and stored in compliance with the Data Protection Act (1998) and the Caldicott Principles (Department of Health, 1997). The present study was combined with a study conducted by a fellow trainee clinical psychologist, who was recruiting from the same participant group but investigating the role of emotional expression.

Inclusion/exclusion criteria

The inclusion criteria were: over 18 years of age, a previous diagnosis of cancer, of any type and stage, completed cancer treatment in the previous two weeks to eight months, non metastatic cancer/curative treatment, able to speak, read and write in English. Given the inclusion of participants with varying cancer diagnoses and treatments, a two-weeks to eight months post-treatment selection criterion was adopted in order to capture the quality of life and psychological well-being outcomes of all patients in the period immediately following cancer treatment as well as in the subsequent months. This selection criterion was also chosen for practical reasons, as it enabled the researchers to contact a larger number of participants within the limited time available for the study.

Exclusion criteria were medical status precluding participation (including blindness, current hospitalisation, unable to write) and those who were currently or had previously been seen by the Mental Health services at the Cancer Centre. Medical notes were accessed to establish whether potential participants met inclusion criteria.

Procedure

A questionnaire pack (including invitation letter, information sheet and questionnaire) was sent out to all the patients who met the inclusion criteria. Those who did not wish to complete the questionnaires were asked to return the questionnaires uncompleted in the pre-paid envelope provided to ensure researchers were aware of their desire not to participate in the study. Individuals who did not return the questionnaire within two weeks of receiving them were sent a reminder letter.

Measures

Demographic questionnaire

Sociodemographic characteristics were gathered including gender, date of birth, ethnicity, religion, marital status, education, occupation, and hours worked before and after cancer diagnosis. Type and stage of cancer diagnosis and treatment(s) received were obtained through medical notes.

The Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002)

The IPQ-R is divided into three sections, with the identity and causal dimensions presented separately from the remaining dimensions (consequences, timeline cyclical/acute, treatment control, personal control, coherence and emotional dimensions). A total of 68 items are included in the questionnaire. These are rated on a scale of 1 (*strongly disagree)* to 5 (*strongly agree).* In the present study the IPQ-R was adapted to assess participants' perceptions about their cancer and comprised seven subscales (the identity subscale was excluded): cause, timeline, consequences, treatment control, personal control, emotional representation and coherence. The questionnaire comprised a total of 52 questions of which 17 questions were regarding the perceived causes of the cancer (e.g. my cancer was caused by stress or worry) rated on a *yes* (1)/*no* (0) scale. Scores relating to causal items were not included in the data analysis since they are used as grouping variables but frequencies of responses were reported. The identity subscale was chosen not to be included in the questionnaire since the sample of participants had differing cancer diagnoses and it was not possible to develop a generic scale that was applicable across a mixed sample. The original version of the IPQ-R was shown to be reliable and valid (the Cronbach alpha's for each of the subscales ranged from 0.79 for the timeline cyclical dimension to 0.89 for the timeline acute/chronic dimension) when tested on a sample of more than 700 patients with eight different groups of illness (Moss-Morris et al.,

2002).

The Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003)

The CD-RISC comprises 25 items used to quantify resilience by measuring five factors (personal competence, trust/tolerance/strengthening effects of stress, acceptance of change and secure relationships, control, spiritual influences). It was created to address aspects of resilience and for use in clinical practice and it measures a person's self-evaluation of prior experience in successfully overcoming stressful events and positive changes. This self-evaluation requires the presence of a stressor or, alternatively, a person's recollection of their response to a previous stressor (Scali et al., 2012). The CD-RISC was designed to be widely applicable to different populations and to assess the extent to which resilience scores can change in response to treatment (Connor & Davidson, 2003).

Each item is scored on a five-point Likert scale ranging from zero (not true at all) to five (true nearly all of the time) and is answered based on the respondents' feelings in the past month. The CD-RISC gives an overall score between 0 and 100, with higher scores representing greater resilience. The CD-RISC has been employed in a number of previous cancer studies (Loprizi, Prasad, Schroeder, & Sood, 2011; Sharpley, Wootten, Bitsika & Christie, 2013). A study of the questionnaire's psychometric properties in general population and patient samples showed adequate internal consistency, test-retest reliability (Cronbach's alpha coefficients of 0.89 in the non-clinical group and 0.87 in the clinical sample), and convergent and divergent validity (Connor & Davidson, 2003). The CD-RISC was chosen as the most appropriate measure of resilience to be adopted given its sound psychometric properties and the relevance to the research question asked.

The Symptom Checklist Revised (SCL-90-R; Derogatis, 1994)

SCL-90-R was used to assess patients' psychological well-being over the past seven days; it is a self-rated 90-item checklist objectively evaluating a broad range of symptoms of psychopathology across nine symptom dimensions (somatization, interpersonal sensitivity, obsessive-compulsive symptoms, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychotism). The global scale (Global Severity Index; GSI) is considered the most reliable indicator of overall distress. Answers are rated on a five point Likert scale ranging from 1 (not at all) to 5 (extremely) where higher scores indicate greater distress. The SCL-90-R has a high reliability and validity (Cronbach's alpha coefficient of 0.97 for the Global Severity Index) (Prinz, Nutzinger, Schulz, Petermann, Braukhaus & Andreas, 2013), and has been used with previous cancer studies (Recklitis, O'Leary, & Diller, 2003; Mulder et al., 2014). This measure was adopted in the present study since it has sound psychometric properties, it has been used in previous cancer studies, it is a good measure of psychopathology and psychological distress and is frequently used in psychotherapy research and clinical practice.

The European Organization for Research and Treatment of Cancer Quality of Life (EORTC QLQ-C30; Aaronson et al., 1993)

The EORTC QLQ-C30 was developed by the European Organization for Research and Treatment of Cancer (EORTC) Study Group on Quality of Life. The EORTC QLQ-C30 is a 30-item self-rated questionnaire that comprises distinct scales, each of which represents a different aspect of QoL (including physical, role, emotional, cognitive and social function and global health status). Additionally, it includes symptom scales measuring fatigue, nausea/vomiting, and six single-item scales: diarrhoea, constipation, appetite loss, insomnia, dyspnoea, and financial difficulties. Answers are rated on a four point Likert scale ranging from 1 to 4. Higher scores define a more positive level of functioning whilst higher scores

indicate a worse level of functioning and more symptoms. Item scores are linearly transformed to range from 0 to 100. The questionnaire has been widely used and found to be a valid and reliable measure of QoL in cancer populations (Cronbach's alpha coefficient >0.70) (Osoba, Zee, Pater, Warr, Kaizer & Latreille, 1994; Jocham, Dassen, Widdershoven & Halfens, 2009; Aaronson et al., 1993). This measure of QoL was chosen since it was developed specifically as a measure of QoL in cancer patients; additionally it measures different aspect of QoL including physical, role, emotional, cognitive and social function and global health status and it has sound psychometric properties as shown in previous research.

Data analysis

All data analysis was carried out using IBM SPSS version 21.0 (Statistical Package for the Social Sciences). First of all, quality control of the data was carried out by looking for data entry errors such as out-of-range values; where maximum or minimum values fell outside the possible range, the participant's questionnaire was checked for the correct score. Where missing data were identified, these were substituted with the mean score on the subscale (where only one score was missing) (Enders, 2010). If two or more scores were missing on a subscale, the participant was excluded from the analysis. Normality testing was carried out via standard Shapiro-Wilk testing; given that the scores on the IPQ-R and SCL-90 were not normally distributed, nonparametric analyses were carried out. All tests were two-tailed. Spearman's rank correlations were used to explore the relationships between IPQ-R, CD-RISC, SCL-90-R and EORTC QLQ-C30 subscale scores. Additionally, Hierarchical Multiple Regression analyses were performed to examine whether illness perceptions and resilience predicted QoL and psychosymptomatology over and above age and type of treatment received. Following each regression model, the results were tested for the assumptions of multiple regression to make sure the data was suitable for this type of analysis. Each model

was checked for the existence of outliers, collinearity of the variables within each model, assumption of independent errors, random normal distribution of the errors, homoscedasticity and linearity of the data, and non-zero variances. To check for outliers, if the standard deviation of our residuals was below -3.29 or above 3.29, the data were observed for potential outliers and any found were considered for removal. For collinearity, the Tolerance and VIF values of the models were observed. If the Tolerance was less than 0.1 or VIF greater than 10 for any variable in the model, these variables were further explored and we determined what variables to keep in the model. For the assumption of independent errors, we looked for a Durbin-Watson value of around 2 from the model results. Anything less than 1 or greater than 3 was considered a violation of this assumption. To assess random normal distribution of the errors, and homoscedasticity and linearity of the data, a few points were observed. First, we looked at a histogram of the residuals to check for normality. Second, we observed a Q-Q Plot of the residuals, and third, we observed a plot of the residuals by the predicted values. Finally, we observed the variances of our variables of interest to determine if these values were 0 or not.

RESULTS

Participant characteristics

Two hundred and forty-seven participants were included in the analyses (135 male, 112 female). Eighty-seven participants had a diagnosis of breast cancer (35.2%), 92 had a diagnosis of prostate cancer (37.2%) and 22 of colorectal cancer (8.9%). Forty-six participants had other types of cancer diagnoses (18.3%) including head and neck cancer (n = 15), skin cancer (n = 11), gynaecological cancer (n = 7), blood cancer (n = 4), lung cancer (n = 3) and bone cancer (n = 1). Information on sociodemographic factors (ethnicity, religion, marital status, academic attainment and work status) are detailed in Table 4 and clinical factors (treatment type, time since treatment and comorbidities) are detailed in Table 5.

Table 4. Sociodemographic factors

Sociodemographic factors		Breast (n = 87)	Prostate (n = 92)	Colorectal (n = 22)	Total group (n = 247)
Gender	Female	100%	0%	55%	45.3%
	Male	0%	100%	45%	54.7%
Mean age		60.8 (12.49)	67.3 (7.86)	64.18 (10.33)	64.72 (11.07)
Ethnicity	White	91.9%	91.3%	86.4%	90.3%
	Black African/Caribbean	2.3%	5.4%	0%	2.8%
	Asian	2.3%	2.3%	13.6%	5.2%
Religion	Atheist	11.9%	11.9%	13.6%	11.6%
	Christian	76.1%	76.1%	59.1%	72.9%
	Sikh	0%	1.1%	0%	2.4%
	Hindu	0%	1.1%	0%	0.4%
	Muslim	13.4%	1.1%	13.6%	2.8%
	Jehovah ‘s Witness	0%	1.1%	0%	0.4%
	Spiritualist	0%	1.1%	0%	0.4%
Marital status	Married	71.2%	73.9%	72.7%	73.8%
	Not married/divorced/widowed	28.8%	26.1%	27.3%	26.2%
Academic attainment	No qualifications	28.5%	40%	57.1%	37.8%
	GCSE equivalent	34.5%	26.6%	14.3%	26.8%
	A level equivalent	16.6%	16.6%	0%	13.0%
	Degree or higher	20.2%	16.6%	28.6%	20.3%
Work status	Full time	18.3%	19.6%	13.6%	16.3%
	Part time	33.3%	20.9%	27.3%	24.3%
	Retired	41.3%	54.9%	50.0%	52.6%
	Homemaker/sick leave/student	4.6%	4.3%	4.5%	5.2%

Table 5. Clinical factors

Clinical factors	Radiotherapy (in isolation or in combination with other treatments)	90.8%	52.2%	36.4%	68.4%
Treatment type					
	Chemotherapy (in isolation or in combination with other treatments)	32.1%	1.1%	9.1%	21.8%
	Surgery (in isolation or in combination with other treatments)	67.8%	51.1%	90.9%	54.6%
Treatment combinations	Radiotherapy only	22.9%	46.7%	0%	34.4%
	Chemotherapy only	3.4%	0%	9.1%	3.2%
	Surgery only	1.1%	46.7%	54.5%	23.1%
	One or more comorbidities	47.3%	47.3%	40.9%	43.2%
	Time since treatment (months)	4.8 (1.5)	4.8 (1.9)	5.5 (1.9)	4.9 (1.7)
	Time since diagnosis (months)	11.6 (5.4)	17.3 (16.7)	9.1 (5.2)	12.9 (9.8)

Power calculations

Power calculation using G-Power 3.1.9 computer programme (Faul, Erdfelder, Lang & Buchner, 2007) (significance set at $p<0.05$, power 0.80, effect size $f^2=0.35$), indicated a sample size of 207 would be needed for the hierarchical multiple regression to achieve significance. The sample size in the present study was therefore sufficiently large to find key effects.

Descriptive statistics for measures obtained

Sample characteristics for the measures obtained are presented according to treatment group (combination of treatment type) (Table 6), cancer type (Table 7) and gender (Table 8) (these analyses were conducted only on variables that were hypothesized to be related to illness perceptions, resilience, quality of life and psychological wellbeing).

After Shapiro-Wilk tests showed that none of our measures were normally distributed within the treatment, cancer, or gender groups, nonparametric Kruskal-Wallis and Wilcoxon Rank-Sum tests were used to observe each of the measures by treatment, cancer type, and gender groups. Results observing outcomes by treatment groups showed that Physical functioning, Fatigue, Dyspnoea, Diarrhoea, and Somatization were significantly different between the treatment groups (all $p < 0.05$) (see Table 6). Results observing outcomes by cancer groups showed that Physical functioning, Role Functioning, Emotional Functioning, Global Health Scale, Fatigue, Pain, Insomnia, Appetite Loss, Diarrhoea, Interpersonal Sensitivity, Anxiety, Hostility, Phobic Anxiety, and Global Scale Index were significantly different between the treatment groups (all $p < 0.05$) (see Table 7). Results showed that average "Emotional Representations" were significantly higher for females (3.5, *SD*=0.9) versus males (3.2, *SD*=0.9), *p*=0.011. Average resilience measures were significantly higher for males (71.3,

SD=14.7) versus females (67.3, *SD* = 14.9), *p*=0.033). Additionally, average fatigue was significantly higher for females (29.4, SD=22.9) versus males (23.0, SD=22.2), p=0.015 (see Table 8).

Table 6. Descriptive statistics (Mean & SD) for the measures obtained (by treatment type)

	Mean (SD) Treatment Groups						
Measure	Surgery (n = 57)	Chemo (n = 85)	Radio (n = 8)	Surgery + Radio (n =153)	Surgery + Radio + Chemo (n =69)	Radio + Chemo (n = 22)	p-value
Illness perceptions							
Consequences	3.9 (0.5)	3.9 (0.6)	4.0 (0.3)	3.7 (0.7)	4.1 (0.7)	4.2 (0.7)	0.18
Emotion representations	3.3 (0.9)	3.2 (0.9)	3.4 (0.9)	3.3 (0.8)	3.5 (0.9)	3.8 (0.8)	0.32
Timeline	2.9 (0.4)	2.9 (0.6)	2.9 (0.3)	2.8 (0.5)	2.8 (0.5)	3.0 (0.6)	0.87
Treatment control	3.9 (0.4)	4.0 (0.5)	3.8 (0.3)	3.9 (0.4)	3.8 (0.6)	4.0 (0.5)	0.61
Coherence	3.0 (0.6)	2.8 (0.6)	2.9 (0.6)	3.0 (0.6)	2.9 (0.6)	3.1 (0.7)	0.59
Personal control	3.4 (0.7)	3.5 (0.5)	3.5 (0.5)	3.4 (0.5)	3.5 (0.5)	3.4 (0.8)	0.94
Resilience	69.1 (15.1)	71.2 (14.8)	66.4 (8.3)	68.5 (13.8)	68.6 (15.8)	69.3 (18.1)	0.85
Quality of life							
Physical functioning	87.6 (15.1)	77.7 (22.7)	92.5 (7.5)	86.1 (15.8)	82.2 (15.0)	76.1 (21.9)	0.02
Role functioning	74.9 (23.6)	76.5 (26.3)	83.3 (17.8)	85.1 (20.7)	82.5 (22.0)	68.1 (32.1)	0.17
Cognitive functioning	84.8 (17.3)	76.1 (22.9)	81.3 (18.8)	81.3 (19.3)	79.4 (21.7)	69.4 (32.4)	0.28
Emotional functioning	77.0 (4.5)	75.7 (25.2)	76.0 (26.4)	82.3 (19.3)	76.2 (24.2)	70.8 (26.7)	0.72
Social functioning	75.7 (25.0)	75.9 (26.3)	70.8 (26.4)	81.9 (22.0)	76.2 (27.2)	63.9 (35.4)	0.56
Global Health Scale	70.6 (21.9)	65.1 (24.0)	74.0 (12.1)	69.3 (21.3)	63.9 (17.1)	62.5 (17.6)	0.41
Fatigue	18.1 (19.0)	27.8 (24.2)	23.6 (17.3)	23.4 (23.3)	31.2 (17.1)	39.8(31.2)	0.01
Nausea	8.2 (13.4)	13.7 (18.9)	12.5 (17.3)	10.8 (14.0)	19.0 (24.3)	12.5 (17.6)	0.42
Pain	15.5 (26.1)	24.3 (30.4)	12.5 (14.8)	19.4 (23.1)	21.4 (22.4)	25.0 (31.4)	0.42
Dyspnoea	9.4 (22.5)	22.0 (29.3)	8.3 (15.4)	15.3 (21.7)	12.7 (19.7)	25.0 (32.2)	0.04
Insomnia	6.4 (19.4)	12.5 (24.1)	12.5 (24.8)	11.8 (26.2)	7.9 (18.0)	30.6 (36.1)	0.07
Appetite loss	0.6 (4.4)	4.3 (15.2)	0.0 (0.0)	4.9 (18.2)	0.0 (0.0)	11.1 (29.6)	0.17
Constipation	23.4 (26.7)	35.7 (34.0)	45.8 (35.4)	28.5 (30.7)	38.1 (33.8)	38.9 (27.8)	0.13
Diarrhoea	15.2 (23.6)	30.6 (31.0)	33.3 (35.6)	19.4 (23.7)	39.7 (32.7)	36.1 (38.8)	0.01
Financial	20.5 (28.7)	21.6 (31.6)	8.3 (23.6)	12.5 (28.0)	27.0 (35.9)	16.7 (26.6)	0.17
Psycho-symptomatology							
Somatization	0.4 (0.5)	0.9 (0.9)	0.5 (0.7)	0.6 (0.7)	0.7 (0.6)	0.9 (0.9)	0.01
OCD	0.5 (0.5)	0.8 (0.8)	0.5 (0.6)	0.6 (0.8)	0.8 (0.8)	1.0 (0.9)	0.16
Interpersonal sensitivity	0.3 (0.6)	0.5 (0.6)	0.5 (0.7)	0.5 (0.8)	0.5 (0.9)	0.7 (0.8)	0.24
Depression	0.6 (0.6)	0.8 (0.8)	0.4 (0.7)	0.6 (0.7)	0.7 (0.8)	0.9 (0.7)	0.19
Anxiety	0.3 (0.5)	0.4 (0.6)	0.4 (0.7)	0.5 (0.7)	0.5 (0.7)	0.7 (0.7)	0.42
Hostility	0.4 (0.6)	0.4 (0.6)	0.1 (0.1)	0.4 (0.7)	0.4 (0.7)	0.4 (0.6)	0.64
Phobic anxiety	0.2 (0.4)	0.3 (0.5)	0.1 (0.2)	0.3 (0.6)	0.3 (0.8)	0.5 (0.9)	0.85
Paranoia	0.2 (0.5)	0.4 (0.6)	0.3 (0.6)	0.2 (0.5)	0.3 (0.7)	0.4 (0.6)	0.12
Psychoticism	0.3 (0.5)	0.4 (0.5)	0.2 (0.3)	0.3 (0.5)	0.3 (0.4)	0.3 (0.2)	0.91
Cognitive deficit	0.5 (0.6)	0.9 (0.8)	0.5 (0.7)	0.7 (0.8)	0.9 (0.9)	1.0 (1.0)	0.18
Global Scale Index	0.4 (0.5)	0.6 (0.6)	0.4 (0.5)	0.5 (0.6)	0.6 (0.7)	0.7 (0.6)	0.18

Table 7. Descriptive statistics for the questionnaire responses (by cancer type)

	Mean (SD)				
Measure	**Prostate (n = 92)**	**Breast (n = 87)**	**Colorectal (n = 22)**	**Other (n =46)**	**p-value**
Illness Perceptions					
Consequences	3.9 (0.5)	3.9 (0.7)	4.0 (0.5)	4.1 (0.5)	0.12
Emotional representations	3.2 (0.9)	3.4 (0.9)	3.3 (0.9)	3.5 (0.8)	0.13
Timeline	2.9 (0.5)	2.8 (0.5)	2.8 (0.4)	2.9 (0.5)	0.43
Treatment control	4.0 (0.5)	3.9 (0.5)	3.8 (0.4)	3.9 (0.5)	0.35
Coherence	2.9 (0.6)	3.0 (0.6)	3.0 (0.7)	2.9 (0.6)	0.83
Personal control	3.4 (0.6)	3.4 (0.5)	3.5 (0.5)	3.4 (0.5)	0.79
Resilience	71.7 (15.6)	69.5 (13.9)	66.8 (12.7)	66.4 (15.8)	0.21
Quality of life					
Physical functioning	86.0 (182)	86.0 (18.2)	79.1 (16.8)	73.2 (24.5)	0.01
Role functioning	77.4 (22.9)	77.4 (22.9)	81.1 (22.6)	67.4 (31.6)	0.03
Cognitive functioning	83.5 (17.7)	83.5 (17.7)	78.0 (23.2)	72.5 (25.9)	0.13
Emotional functioning	81.8(19.5)	81.8 (19.5)	66.3 (28.6)	69.4 (29.5)	0.03
Social functioning	76.5 (22.4)	75.4 (24.8)	73.5 (26.6)	68.8 (30.3)	0.09
Global Health Scale	66.8 (20.7)	70.9 (23.5)	64.0 (19.0)	61.4 (19.5)	0.02
Fatigue	25.9 (22.6)	19.1 (19.1)	31.3 (22.4)	35.7 (29.2)	0.01
Nausea	12.1 (17.1)	9.2 (16.3)	15.2 (17.7)	15.6 (18.4)	0.09
Pain	20.6 (26.7)	14.3 (24.4)	30.3 (31.1)	27.2 (30.9)	0.01
Dyspnoea	16.6 (25.8)	12.7 (22.6)	19.7 (32.0)	23.9 (30.4)	0.14
Insomnia	11.5 (24.3)	4.7 (13.6)	7.6 (20.4)	30.4 (35.7)	< 0.0001
Appetite loss	3.1 (13.9)	1.1 (6.0)	3.0 (9.8)	10.9 (28.2)	0.02
Constipation	32.5 (32.1)	29.3 (30.8)	30.3 (28.9)	34.1 (32.6)	0.65
Diarrhoea	26.4 (29.7)	19.2 (25.8)	31.8 (33.3)	37.0 (30.8)	0.01
Financial difficulties	20.1 (30.2)	18.5 (29.0)	33.3 (30.9)	23.2 (35.0)	0.06
Psychosymptomatology					
Somatization	0.6 (0.7)	0.6 (0.7)	0.7 (0.7)	0.9 (1.0)	0.07
Obsessive compulsive	0.6 (0.7)	0.6 (0.6)	0.5 (0.7)	1.0 (1.0)	0.07
Interpersonal sensitivity	0.4 (0.6)	0.4 (0.6)	0.5 (0.7)	0.8 (0.9)	0.01
Depression	0.6 (0.6)	0.6 (0.7)	0.6 (0.7)	1.0 (0.9)	0.05
Anxiety	0.3 (0.5)	0.4 (0.5)	0.4 (0.5)	0.7 (0.9)	0.03
Hostility	0.4 (0.6)	0.3 (0.4)	0.4 (0.6)	0.6 (0.8)	0.03
Phobic anxiety	0.2 (0.4)	0.2 (0.5)	0.1 (0.2)	0.6 (0.9)	0.01
Paranoia	0.3 (0.5)	0.2 (0.4)	0.2 (0.5)	0.6 (0.9)	0.05
Psychoticism	0.4 (0.5)	0.2 (0.3)	0.2 (0.4)	0.5 (0.6)	0.07
Cognitive deficit	0.7 (0.7)	0.7 (0.7)	0.6 (0.6)	1.0 (1.0)	0.23
Global Scale Index	0.4 (0.5)	0.5 (0.5)	0.5 (0.5)	0.8 (0.8)	0.03

Table 8. Descriptive Statistics and Wilcoxon Rank-Sum Results for the Measures (by gender)

	Mean (SD)		
Measure	**Male (n = 135)**	**Female (n = 112)**	**p-value**
IPQ-R			
Consequences	3.9 (0.5)	3.9 (0.6)	0.91
Emotional representations	3.2 (0.9)	3.5 (0.9)	0.01
Timeline	2.9 (0.5)	2.8 (0.5)	0.53
Treatment control	3.9 (0.5)	3.8 (0.5)	0.05
Coherence	2.9 (0.6)	2.9 (0.6)	0.95
Personal control	3.5 (0.6)	3.4 (0.5)	0.18
Resilience	71.3 (14.7)	67.3 (14.9)	0.03
Quality of life			
Physical functioning	82.3 (21.2)	82.1 (16.1)	0.17
Role functioning	75.9 (25.7)	80.5 (22.8)	0.21
Cognitive functioning	81.5 (20.6)	76.9 (22.8)	0.12
Emotional functioning	78.1 (23.2)	75.9 (24.9)	0.47
Social functioning	73.6 (26.7)	79.3 (23.7)	0.09
Global health status	68.5 (23.0)	65.6 (19.8)	0.11
Fatigue	23.0 (22.2)	29.4 (22.9)	0.01
Nausea	11.7 (17.4)	12.4 (17.0)	0.64
Pain	19.3 (28.0)	22.2 (25.2)	0.10
Dyspnoea	16.5 (27.0)	16.7 (24.5)	0.70
Insomnia	9.9 (22.7)	13.4 (26.3)	0.26
Appetite loss	2.5 (10.5)	3.9 (26.3)	0.89
Constipation	29.4 (29.9)	36.3 (34.2)	0.14
Diarrhoea	24.4 (29.1)	28.3 (30.4)	0.29
Financial difficulties	19.8 (30.3)	20.5 (30.4)	0.74
Psychosymptomatology			
Somatization	0.6 (0.8)	0.7 (0.7)	0.21
Obsessive compulsive	0.7 (0.7)	0.7 (0.7)	0.55
Interpersonal sensitivity	0.4 (0.6)	0.5 (0.8)	0.33
Depression	0.7 (0.7)	0.8 (0.8)	0.72
Anxiety	0.4 (0.6)	0.5 (0.7)	0.075
Hostility	0.4 (0.6)	0.3 (0.6)	0.18
Phobic anxiety	0.2 (0.5)	0.3 (0.7)	0.22
Paranoia	0.3 (0.6)	0.3 (0.6)	0.23
Psychoticism	0.3 (0.5)	0.3 (0.5)	0.99
Cognitive deficit	0.7 (0.8)	0.8 (0.8)	0.75
Global Scale Index	0.5 (0.6)	0.6 (0.6)	0.28

IPQ-R Cause subscale

The mean scores for each of the cause items are shown in Table 9. 'Chance or bad luck' was the most strongly endorsed cause for cancer, followed by ageing and stress and worry. The least favoured attributions were mental attitude e.g. thinking about life negatively and personality.

Table 9. Responses for each of the cause items from the self-regulation model

Attribution/cause	N (%)
Stress/worry	50 (21.3%)
Hereditary/runs in the family	45 (19.4%)
Germ or virus	16 (6.8%)
Eating habits	31 (12.9%)
Chance or bad luck	154 (65%)
Poor medical care in the past	15 (6.4%)
Pollution in the environment	29 (12.3%)
Mental attitude e.g. thinking about life negatively	7 (2.9%)
Family problems or worries	27 (11.3%)
Overworking	17 (7.2%)
Emotional state e.g. feeling down, lonely, anxious, empty	18 (7.5%)
Ageing	99 (41.4%)
Alcohol	16 (6.6%)
Smoking	16 (6.6%)
Personality	6 (2.5%)
Altered immunity	31 (13.1%)
Pressure at work	18 (7.5%)

Correlation analysis

Correlations between the IPQ-R subscales, the total resilience score (CD-RISC), the quality of life score (EORTC QLQ-C30 Global Health Status) and the SCL-90 depression, anxiety and global symptom index scores are presented in Table 10. Significant relationships (weak to moderate) between the scales were apparent. Greater scores on the IPQ-R consequences subscale were significantly associated with poorer physical functioning, role functioning, cognitive functioning, emotional functioning, social functioning, and the global health scale on the EORTC QLQ-C30. IPQ-R consequences were positively associated with fatigue, nausea, pain, dyspnoea, insomnia, constipation, diarrhoea, and financial difficulties on the EORTC QLQ-C30. The IPQ-R consequences subscale was positively associated with somatisization, obsessive compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoia, psychoticism, cognitive deficit and global scale index on the SCL-90.

Greater scores on the emotional representations subscale of the IPQ-R were significantly associated with poorer physical functioning, role functioning, cognitive functioning, emotional functioning, social functioning, and the lower scores on the global health scale on the EORTC QLQ-C30. IPQ-R emotional representations were positively associated with fatigue, nausea, pain, appetite loss, insomnia, constipation, diarrhoea, and financial difficulties on the EORTC QLQ-C30. The IPQ-R emotional representations subscale was positively associated with somatisization, obsessive compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoia, psychoticism, cognitive deficit and global scale index on the SCL-90.

Greater scores on the IPQ-R timeline subscale were significantly associated with poorer role functioning, cognitive functioning, emotional functioning, social functioning, and lower

scores on the global health scale on the EORTC QLQ-C30. IPQ-R timeline subscale was positively associated with pain, dyspnoea, financial difficulties on the EORTC QLQ-C30. The IPQ-R timeline subscale was positively associated with somatisization, obsessive compulsive, depression, hostility, phobic anxiety, psychoticism, cognitive deficit and global scale index on the SCL-90.

There were significant positive associations between the treatment control subscale of the IPQ-R and emotional functioning and the global health scale on the EORTC QLQ-C30. Greater scores on the IPQ-R treatment control subscale were associated with lower scores on the pain, diarrhoea and financial difficulties subscales of the EORTC QLQ-C30. Greater scores on the IPQ-R treatment control subscale were significantly associated with lower scores on the somatisization, depression, phobic anxiety, psychoticism subscales of the SCL-90.

There were significant associations between greater perceived coherence on the IPQ-R and higher social functioning, nausea and diarrhoea on the EORTC QLQ-C30. Greater perceived coherence was also associated with lower scores on the depression and paranoia scales of the SCL-90.

There were significant positive associations between IPQ-R personal control and the global health scale on the EORTC QLQ-C30. Poorer scores on the personal control subscale of the IPQ-R were associated greater scores on the ‘appetite loss’ subscale of the EORTC QLQ-C30 and with greater scores on the phobic anxiety subscale of the SCL-90.

Greater resilience scores were significantly correlated with lower scores on the emotional representations subscale of the IPQ-R. Resilience was also significantly positively correlated with IPQ-R treatment control. Additionally, resilience was significantly positively associated with the Global Health Status score on the EORTC QLQ-C30 and was significantly

associated with lower scores on the anxiety, depression and Global Scale Index of the SCL-90.

Table 10. Spearmans Rho correlations between age, IPQ-R, CD-RISC, EORTC, QLQ-C30 and SCL90-R subtests.

	EORTC Global Health Status	SCL90 Depres	SCL90 Anxiet	SCL90 GSI	Resilie.	IPQ-R Conseq	IPQ-R Emot repres	IPQ-R Timeli	IPQ-R Treatm. control	IPQ-R Coheren	IPQ-R Person control	Age
EORTC Global Health Status	-											
SCL90 - Depression	-.57**	-										
SCL90 Anxiety	-.53**	.80**	-									
SCL90 GSI	-.58**	.94**	.86**	-								
Resilience	.33**	-.37**	-.41**	-.35**	-							
IPQ-R Consequences	-.24**	.35**	.26**	.34**	-.09	-						
IPQ-R Emotional representations	-.26**	.36**	.39**	.36**	-.41**	.53**	-					
IPQ-R Timeline	-.16**	.17**	.08	.13*	-.10	.25**	.29**	-				
IPQ-R Treatment control	.23**	-13**	-.08	-.10	.17**	-.05	-14*	-.28**	-			
IPQ-R Coherence	.10	-.14*	-.11	-.11	.07	-.03	-.17**	-.12	-.01	-		
IPQ-R Personal control	.12	-.05	-.06	-.01	.12	.14*	-.04	-.10	.28**	.02	-	
Age	.07	-.16**	-.20**	-.16**	0.6	-.31**	-.25**	-.06	.20	-.13*	-.12*	-

*p < 0.05 **;** **p < 0.01.

T-Tests and Shapiro-Wilk tests

We thought it would be interesting to investigate differences between the two main cancer groups (breast and prostate) to see whether these differed significantly on measures of quality of life, psychosymptomatology and resilience. We thought that this would also be helpful in interpreting the results of the hierarchical multiple regression analysis carried out in the breast and prostate groups separately (Appendices C, D, E & F). Table 11 displays the results of tests carried out between the prostate and breast cancer subgroups and illustrates the means and standard deviations for each group and significant differences on the measures of quality of life, psychosymptomatology and resilience. Shapiro-Wilk tests were used to observe normality of each measure between the prostate/breast cancer groups. Age and CD-RISC were normally distributed between the groups, therefore a Two-Sample t-test was used. All of the other measures were not normally distributed, therefore a Wilcoxon-Rank Sum test was used. Significant differences were found between the two groups in age *(t* = 4.2, *p* <0.0001). Significant differences were also found in Fatigue (*Z* = 2.6, p = 0.009), and Pain (*Z* = 2.7, *p* = 0.008). For both Fatigue and Pain, Breast Cancer measures were significantly higher than Prostate.

Table 11. Resilience, quality of life and psychological symptoms split according to breast cancer and prostate cancer groups of patients (t-test results)

Dependent variable		**Prostate cancer group N = 92**	**Breast cancer group N = 87**		
		Mean (SD)	**Mean (SD)**	***Test Statistic (t or Z)***	***p***
AGE		**67.3 (7.9)**	**60.8 (12.5)**	**4.2**	**<0.0001***
CD-RISC	Total	71.7 (15.6)	69.5 (13.9)	1.0	0.32
EORTC QLC-30	Role functioning	77.4 (22.9)	83.5 (20.6)	1.9	0.06
	Cognitive functioning	83.5 (17.7)	79.1 (22.2)	-1.1	0.28
	Social Functioning	75.4 (24.8)	81.6 (22.3)	1.8	0.08
	Fatigue	**19.1 (19.1)**	**26.4 (20.3)**	**2.6**	**0.01**
	Nausea	9.2 (16.3)	12.3 (17.1)	1.4	0.16
	Pain	**14.3 (24.4)**	**21.3 (24.2)**	**2.7**	**0.01**
	Dyspnoea	12.7 (22.6)	16.1 (24.3)	1.1	0.28
	Insomnia	4.7 (13.6**)**	9.6 (22.1**)**	1.5	0.14
	Appetite loss	1.1 (6.0)	1.1 (6.1)	0.1	0.95
	Constipation	29.3 (30.8)	35.6 (34.0)	1.2	0.24
	Diarrhoea	19.2 (25.8)	26.4 (30.6)	1.5	0.12
	Financial difficulties	18.5 (29.0)	16.9 (28.2)	-0.4	0.69
	Global health status	70.9 (23.5)	67.0 (20.7)	-1.6	0.11
SCL90-R	Somatization	0.6 (0.7)	0.6 (0.7)	1.6	0.12
	Obsessive compulsive	0.6 (0.6)	0.6 (0.6)	0.8	0.45
	Interpersonal sensitivity	0.4 (0.6)	0.4 (0.6)	0.9	0.38
	Depression	0.6 (0.6)	0.6 (0.7)	-.01	0.99
	Anxiety	0.3 (0.5)	0.4 (0.5)	1.5	0.12
	Hostility	0.4 (0.6)	0.3 (0.4)	-1.2	0.23
	Phobic anxiety	0.2 (0.4)	0.2 (0.5)	1.0	0.32
	Paranoid ideation	0.3 (0.5)	0.2 (0.4)	-0.9	0.36
	Psychoticism	0.4 (0.5)	0.2 (0.3)	-1.0	0.31
	Cognitive deficit	0.7 (0.7)	0.7 (0.7)	0.6	0.54
	GSI	0.4 (0.5)	0.5 (0.5)	1.1	0.26

Regression analyses

Univariate regression analyses were run separately observing age, gender, marital status, time since treatment, time since diagnosis, and treatment type (surgery yes/no, chemotherapy yes/no, and radiotherapy yes/no) received, by the dependent variables (SCL90-R, EORTC QLQ-C30, CD-RISC, IPQ-R).

Age was found to be a significant predictor of the Global Symptom Index on the SCL90-R ($F(1, 241) = 12.29$, $p < 0.001$) and a significant predictor of the consequences subscale on the IPQ-R ($F(1, 246) = 31.65$, $p < 0.001$), the emotion representations scale on the IPQ-R ($F(1, 262) = 19.15$, $p < 0.001$) and personal control scale on the IPQ-R ($F(1, 246) = 4.59$, $p < 0.05$). Age however was not a predictor of EORTC QLQ-C30 scores or CD-RISC scores.

Time since diagnosis significantly predicted scores on the emotional representations scale of the IPQ-R ($F(1, 121) = 7.81$, $p < 0.01$), on the timeline scale of the IPQ-R ($F(1, 121) = 4.67$, $p < 0.05$) and on the coherence scale of the IPQ-R ($F(1, 121) = 4.99$, $p < 0.05$). Time since diagnosis did not significantly predict any of the other dependant variables.

Time since treatment significantly predicted coherence scores on the IPQ-R ($F(1, 244) = 6.89$, $p<0.05$) but did not significantly predict any of the other dependant variables.

Having received radiotherapy treatment significantly predicted Global Symptom Index on the SCL90-R ($F(1, 236) = 4.18$, $p < 0.05$) but did not significantly predict any of the other dependant variables.

Having received chemotherapy significantly predicted scores on the consequences subscale of the IPQ-R ($F(1, 241) = 4.87$, $p < 0.05$) and on the emotional representations subscale of the

IPQ-R ($F(1, 241) = 4.12$, $p < 0.05$) but did not significantly predict any of the other dependant variables.

Gender was found to be a significant predictor of the emotion representations scale on the IPQ-R ($F(1, 246) = 5.79$, $p < 0.05$) but did not significantly predict any of the other dependant variables.

Marital status was found to be a significant predictor of the treatment control subscale of the IPQ-R ($F(1, 246) = 9.28$, $p < 0.005$) and of the personal control subscale of the IPQ-R ($F(1, 246) = 8.06$, $p < 0.005$). Marital status did not significantly predict any of the other dependant variables.

Hierarchical multiple regression

Hierarchical multiple regression analyses were performed to examine whether illness perceptions and resilience predicted QoL and psychosymptomatology over and above age and type of treatment received. Age and treatment type received were included in the multiple regression because these variables were significant in the univariate regression analyses. These analyses were carried out for the cancer group as whole and subsequently the subgroup of prostate cancer patients and the subgroup of breast cancer patients. The results of the secondary analyses in the prostate and breast cancer subgroups are included in the appendices (C, D, E & F) and are not discussed in the current study.

All final models were checked for assumptions/diagnostics of multiple regression, including the existence of outliers, collinearity of the variables, assumption of independent errors, random normal distribution of the errors, homoscedasticity and linearity of the data, and non-zero variances. Results showed all assumptions were met and there were no outliers to assess or collinearity.

In each analysis, a forward-selection approach was used to create each multivariable model. Age and type of treatment received were entered on the first step. The components of the self-regulation model were entered on the second step and in order to determine whether resilience improves the ability to predict quality of life and psychological well-being beyond the components of the self regulation model, resilience was entered on the third step.

As shown in Table 12, age and type of treatment received were not significant predictors of QoL. The components of the self regulation model increased the adjusted R-Squared to 9.2%, $F(10, 230) = 3.43$, $p<0.01$. The adjusted R-Squared in QoL was again increased to 16.2% with the addition of resilience, $F(11, 229) = 5.21$, $p<0.001$. A test comparing the R-Squared values in the nested models showed that none of the increases were statistically significant. The strongest predictors of QoL were resilience and perceived consequences, followed by perceived treatment control (Table 12).

As shown in Table 13, our first model explained 6.2% of the variability in psychosymptomatology $F(4, 231) = 4.85$, $p < 0.001$. The components of the self regulation model increased the R-Squared to 16.9%, $F(10, 225) = 5.79$, $p<0.001$. The explained variability in psychosymptomatology was increased to 24.3% with the addition of resilience, $F(11, 224) = 7.86$, $p<0.001$. A test comparing the R-Squared values in the nested models showed that none of the increases were statistically significant. The strongest predictors of psychological distress were resilience, then age and perceived consequences, followed by emotional representations. (Table 13).

Table 12. Hierarchical multiple regression analysis for the predictors of quality of life (Global Health Scale) in cancer patients

Step/predictor	R^2	Adjusted R^2	F	β in final equation	p-value for Comparison of Nested Models
1. Demographic and clinical factors	.019	.002	1.124		
Age				.07	
Surgery				.06	
Chemotherapy				-.01	
Radiotherapy				-.09	
2. Self-regulation model	.13	.092	3.43		0.111
Consequences				-.23*	
Emotional representations				-.04	
Timeline				.01	
Treatment control				.18*	
Coherence				.04	
Personal control				.08	
3. Resilience	.19	.162	5.21	.29*	0.071

*p<.01; ** p<.001.

Table 13. Hierarchical multiple regression analysis for the predictors of psychosymptomatology (Global Symptom Index) in cancer patients

Step/predictor	R^2	Adjusted R^2	F	β in final equation	p-value for Comparison of Nested Models
1. Demographic and clinical factors	.078	.062	4.852	-.25**	
Age				-.12	
Surgery				-.02	
Chemotherapy				-.9	
Radiotherapy					
2. Self-regulation model	.205	.169	5.795		0.126
Consequences				.19*	
Emotional representations				.19*	
Timeline				.01	
Treatment control				.08	
Coherence				.07	
Personal control				.05	
3. Resilience	.278	.243	7.860	-.30**	0.074

*p<.01; ** p<.001.

DISCUSSION

Summary of findings

This study aimed to investigate the relationship between illness perceptions, resilience, QoL and psychological well-being in cancer survivors. It was hypothesised that more negative illness perceptions would be associated with poorer QoL and poorer psychological well-being. Secondly, it was hypothesised that resilience would be associated with more positive illness perceptions (i.e. perceptions of cancer as being more controllable, more coherent, perceptions of less negative consequences, a less chronic/acute timeline and being less emotionally loaded). Thirdly, it was hypothesised that greater resilience and more positive consequences, control and emotional representations illness perceptions would significantly predict better QoL and psychological well-being in cancer survivors.

Firstly, negative perceived consequences, emotional representations and timeline were found to be associated with greater levels of psychological distress and poorer QoL. Additionally, greater treatment control was associated with a greater QoL. These results are consistent with previous research that shows that more negative illness perceptions (such as emotional representations, identity, consequences and timeline) are related to more maladaptive outcomes (e.g. poorer social and role functioning and psychological distress) (Hagger & Orbell, 2003; Hampson, 1997; McSharry et al., 2011). Furthermore, previous research shows that negative perceived consequences have been associated with poorer psychological well-being and poorer QoL outcomes in cancer patients as well as in other physical health populations (Hagger & Orbell; 2003, Scharloo et al., 2007, Trager et al., 2009) and negative beliefs in a chronic timeline have been associated with poorer QoL (Scharloo et al., 2007).

The present study's findings are also in line with previous research reporting associations between positive treatment control beliefs and a greater QoL (Jorgensen et al., 2009).

Secondly, it was hypothesised that resilience would be associated with a more positive profile of illness perceptions. Lower resilience scores were significantly associated with negative emotional representations whilst higher resilience scores were significantly associated with perceptions of greater treatment control and personal control. No previous studies have explored the relationship between resilience and illness perceptions in cancer patients. Research in other physical health populations is scarce but associations have been found between greater resilience and smaller perceived consequences in women experiencing hot flushes or night sweats during menopause (Duffy, Iversen, Aucott & Hannaford, 2013). Several studies have found significant associations between self-efficacy and resilience (Smith & Zautra, 2008; Schiaffino & Revenson, 1992; Yi, Vitaliano, Smith, Yi & Weinger, 2008) across various physical health populations; one could speculate that greater perceived treatment and personal control could be related to self-efficacy. Interest in understanding the relationship between resilience and illness perceptions in physical health populations is growing (Duffy et al., 2013; Chew, Shariff-Ghazali & Fernandez, 2014).

Thirdly, it was hypothesised that illness perceptions (consequences, control and emotional representations) and resilience would significantly predict QoL and psychological well-being in cancer survivors. The results of the hierarchical regression revealed that both resilience and some of the individual components of the self-regulation model were able to predict QoL and psychosymptomatology in cancer survivors. The strongest predictors of QoL were resilience and perceived consequences, followed by perceived treatment control. The strongest predictors of psychological distress were resilience and age, followed by perceived

consequences and emotional representations. The results of the regression analyses showed that the only illness perception subscales that made significant unique contributions to the variance in outcome scores were perceived consequences, emotional representations and treatment control.

These findings fit with psychological theories, which describe how people's perceptions of, or thoughts about, situations influence their emotional, behavioural (and often physiological) reactions (e.g. Beck et al., 1979; Beck, 1995). The cognitive behavioural model can be helpful in conceptualising the findings of the present study; according to this model negative thoughts can lead to experiencing a variety of feelings including sadness, anger or anxiety; these in turn can have an impact on bodily sensations (e.g. feeling tense, tired or lethargic) and can influence her behaviours (e.g. becoming isolated). These in turn can lead to more negative thoughts, which in turn lead to feelings of low mood.

The results from the present study are consistent with the possibility of models that suggest that illness perceptions may have an impact on quality of life and psychological wellbeing through the mediation of the emotional and behavioural impact they have. According to such models, the experience of negative emotional representations in cancer survivors can affect their cognitions and behavioural reactions, in turn leading to poorer quality of life and poorer psychological wellbeing. Furthermore, lower beliefs in treatment control in cancer survivors could be related to beliefs about a more negative outcome and consequences as well as more negative emotional representations, which in turn leads to poorer outcomes (psychological wellbeing and quality of life). However, further research is needed in order to establish this possibility.

In a similar way, Leventhal's Common Sense model can be a helpful framework in conceptualising the findings of the present study. According to this model, illness representations guide a person's evaluation of an illness situation and their behaviours in response to this situation. Two processing systems work simultaneously; one system is dedicated to the cognitive processing of stimuli (external or internal) and the other system is dedicated to the emotional processing of the same stimuli. As a consequence, both cognitive and emotional processes can trigger health behaviours (Leventhal, Diefenbach & Leventhal, 1992). The thought of cancer in itself is often a trigger of cognitions about suffering and potentially life-threatening consequences and prolonged treatment with uncertain outcomes. These representations triggered by thoughts of cancer can simultaneously trigger an intense emotional reaction of anxiety and fear. Therefore, a cancer survivors' experience of negative illness representations about the consequences of cancer and/or treatment control could lead to the person's emotional reactions during these cognitive processes, as conceptualized in the parallel processing model, to change, resulting in a poorer quality of life and poorer psychological wellbeing. Likewise, negative emotional representations of cancer are likely to lead to a poorer quality of life and poorer psychological wellbeing in cancer survivors.

The findings of the present study also fit with previous research that shows that resilience predicts QoL and psychological well-being both in those with cancer (Sharpley, Bitsika, Wooten & Christic, 2014; Ryu & Yi, 2013; Min et al., 2013; Strauss et al., 2007) and in other clinical and non-clinical populations (Bonanno, 2005; Mautner, 2013; Nygren, Aléx, Jonsén, Gustafson, Norberg & Lundman, 2005; Hildon, Montgomery, Blane, Wiggins & Netuveli, 2009). Previous research shows that several other factors have a role in reducing the risk of developing depression in cancer patients. These include factors like hopefulness (Vellone,

Rega, Galletti & Cohen 2006), spirituality (Wenzel, Donnelly, Fowler, Habbal, Taylor, Aziz, & Cella, 2002) and family/social support (Orbuch, Parry, Chesler, Fritz, & Repetto, 2005, Kroenke, Kubzansky, Schernhammer, Holmes & Kawachi 2006). Resilience has also been found to be the strongest predictor of fatigue early in radiotherapy treatment, suggesting that the psychological ability to manage stress related to threat and illness can also influence levels of fatigue (Strauss et al., 2007). Resilience could be seen as a buffer variable between stress and depression (Luthar & Cicchetti 2000); the present study supports previous research that suggests that resilience may be a protective factor for cancer patients' mental well-being (Luthar & Cicchetti 2000; Min et al., 2013) by independently contributing to low emotional distress in cancer patients (Min et al., 2013).

The present study also highlighted interesting relationships between resilience and IPQ variables; resilience was associated with perceptions of cancer as being less emotionally loaded and it was also associated with perceptions of cancer treatment being more controllable. This may be because people with higher resilience scores have a greater capacity to 'bounce back in the face of adversity' and have a more positive outlook on negative situations (i.e. illness and treatment), leading to more positive cognitions about treatment control and to perceptions of cancer as being less emotionally loaded. Greater resilience and more positive beliefs regarding treatment control and emotional representations of cancer also predicted better quality of life and psychological well-being in cancer survivors. So this study has identified a potential explanatory link between illness perceptions and quality of life using resilience.

The results of the present study also replicate previous findings that illustrate significant relationships between on the one hand negative illness perceptions and, of the other hand, poorer QoL and lower mood in cancer patients (Silva et al., 2012; Gould et al., 2010; Rozema

et al., 2009; McCorry et al., 2013; Jorgensen et al.; 2009). Research has shown that illness perceptions can explain a significant proportion of variance in levels of distress in cancer populations (Llewellyn et al., 2007; Scharloo et al., 2005; Millar et al., 2005) as well as in other chronic illnesses (e.g. Cartwright et al., 2009; Dorrian et al., 2009). Studies in cancer patients have found that negative illness perceptions predict worse health-related QoL and depression after treatment (Chaboyer, Lee, Wallis, Gillespie & Jones, 2010; Traeger, Penedo & Gonzalez 2009) and timeline perceptions have been found to predict distress at six and 12 months following breast surgery (Millar et al., 2005). Additionally, higher levels of anxiety and depression have been found in female cancer patients who hold stronger beliefs in chronic and cyclical timeline, more severe consequences, more symptoms and lower personal and treatment control and a less coherent understanding of the illness (Mc Corry et al., 2013). Previous research has identified differences between cancer types and time since treatment, with skin cancer survivors reporting less negative consequences and patients who had recently received cancer treatment experiencing more negative consequences and greater perceptions of timeline chronicity (Hopman & Rijken, 2015). Additionally, characteristics such as illness duration and treatment type/stage may have an impact on cancer patients' experiences and influence their illness perceptions (Hopman & Rijken, 2015). Different levels of perceived personal control have in fact been found in short-term and long-term colorectal cancer survivors (Mols et al., 2012).

In the present study treatment type did not predict quality of life or psychological well-being; this may be due to the majority of participants having received radiotherapy treatment in combination with other treatments. It was therefore not possible to clearly differentiate between the chemotherapy, radiotherapy or surgery treatment groups and it is possible that the

effects of treatment were hidden due to having a combination of treatments or by the length of time since treatment.

Strengths and limitations

This study is the first to explore the relationship between resilience and illness perceptions in cancer patients. The results show that greater resilience is associated with perceptions of greater treatment control and personal control whilst negative emotional representations are associated lower resilience. These findings add to the existing literature that explores the effects of illness perceptions and resilience on psychological well-being and quality of life in cancer patients. The sample size in the present study was sufficiently large to find key effects whilst minimising type II errors.

There are a number of limitations to this study. Firstly there may have been a self-selecting sample bias; information was not gathered on why non-responders chose not to take part. The reasons for which some patients chose not to participate may have been due to distress or physical health problems; this information would have been useful in understanding differences between responders and non-responders and understanding whether the differences had an impact on the results.

Secondly, the majority of the participants who took part in the study had received radiotherapy treatment alone (34.4%) or in combination with other treatments (34%); this was due to the recruitment procedure and the assistance of radiotherapy nurses who helped identify eligible participants. The remaining participants (31.6%) received other treatments (chemotherapy and/or surgery but not radiotherapy). This may limit the generalisability of the findings to patients who have undergone primarily surgery or chemotherapy treatments and it

makes it more difficult to identify the differences in illness perceptions and resilience in these different treatment groups.

Thirdly, there was a great variability within the patient group in terms of time since diagnosis, number of treatments and treatment combinations received, as it is difficult to control for all these variables when working with this kind of population. Since the participants in the current study had non-metastatic cancer and took part in the study within eight months of completing cancer treatment, caution must be made when generalising these results to other cancer populations (e.g. terminally ill patients) as their resilience and illness perceptions may well be different (Monroe & Oliviere, 2007; Temel et al., 2011).

Another limitation is that social support was not assessed in the present study. Social support has been related to less severe perceptions of consequences of illness and greater perceptions of control in breast cancer patients (Awasthi et al., 2006) whilst a lack of social support has been linked to poor psychological outcomes in cancer patients (Kroene et al., 2006; Luszczynskaa, Mohamed & Schwarzer, 2005; Hipkins et al., 2004).

Clinical implications

This research could have significant clinical implications; not only in terms of identifying cancer survivors who may be more vulnerable to psychological distress but also in terms of informing the development of clinical interventions aimed at improving patients' psychological well-being by targeting unrealistic or negative illness perceptions, correcting unhelpful beliefs, enhancing perceptions of control and promoting resilience. Assessing for levels of resilience soon after diagnosis may help with the identification of vulnerable patients. Resilience training has been evaluated in previous research in different clinical and

non-clinical populations with meaningful outcomes including greater resilience scores, improved coping strategies and improved psychological well-being (Steinhardt & Dolbier, 2008; Bradshaw et al., 2007; Waite & Richardson, 2004; Loprinzi et al., 2011). The Stress Management and Resilience Training (SMART) program has been found to significantly improve resilience and reduce stress and anxiety in a group of breast cancer patients (Loprinzi et al., 2011). Resilience training is often structured as a psycho-educational programme designed to enhance personal and social skills/resources and enhance adaptive coping strategies and protective factors (Dolbier et al., 2010). The overall aim of the training is that of increasing resilience by drawing on psychological approaches including cognitive behavioural therapy, rational-emotive therapy and family therapy (Dolbier et al., 2010).

Increasingly, research emphasizes the importance of understanding patients' illness perceptions in order to improve their psychosocial well-being (Cameron et al., 1998; Millar et al, 2005; Scharloo et al., 2005; Broadbent et al., 2009). Research shows that interventions (three sessions of approximately one hour) aimed at modifying illness perceptions in other populations (e.g. myocardial infarction and diabetes) have been found to lead to better health-related outcomes (for example improved rates of return to work and lower levels of distress) (Broadbent et al., 2009; Skinner et al., 2006; Chilcot & Moss-Morris, 2013; Petrie et al., 2002). Interventions using cognitive-behavioural techniques have also been found to lead to improvements in participants' illness perceptions of treatment control, reductions in perceptions of the negative emotional impact of the condition and reductions in stress levels in Systemic Lupus Erythematosus (Goodman et al., 2005). Additionally, interventions have been shown to change/improve illness perceptions related to timeline chronicity, severity of consequences and poor perceived control as well as improve physical symptomatology in patients who have experienced myocardial infarction (Petrie et al., 2002).

Assessment of illness perceptions can be carried out quickly and easily and can be helpful in providing guidance to health care planning and can potentially support the identification of patients at greater risk of negative psychosocial outcomes. Appropriate information about which symptoms and which consequences to expect seems important (Rozema et al., 2009) since satisfaction with information provided has been associated with better outcomes, including more positive illness perceptions in cancer patients (Iskandarsyah et al., 2013).

Future research

Stronger evidence is required to better understand changes in illness perceptions and resilience over time and at different stages of a patient's illness trajectory. Qualitative and quantitative longitudinal studies are required to examine how changes in illness perceptions and resilience are related to changes in psychological distress and quality of life (by measures being completed at various time points) and in order to understand whether baseline resilience has a long-term impact on cancer survivors' well-being. Additionally, qualitative studies exploring cancer survivors' beliefs about what makes them more resilient would be useful in further understanding the concept of resilience in cancer patients and guiding future research in this area. Further research is required in order to replicate this study in other cancer types, in other treatment types, in patients with metastatic cancer and in patients receiving palliative care. It may be interesting to repeat the study also in specific cancer groups and/or treatment types in order to better understand the impact of illness perceptions and resilience on psychological well-being and QoL in more clearly defined groups.

Studies using prospective and longitudinal designs are required in order to understand the temporal dimensions of the self-regulatory model across two or more points in time and in

order to identify further relationships between illness perceptions, psychological well-being and quality of life.

Conclusions

The present study supports previous research that suggests that resilience is an important predictor of quality of life and psychological well-being in cancer survivors. Furthermore, the results illustrate significant relationships between negative illness perceptions, poorer QoL and lower mood in cancer patients. Additionally, resilience was found to be associated with perceptions of cancer as being more controllable and less emotionally loaded. This research could have significant clinical implications; addressing negative illness perceptions and psychological resilience could be beneficial to cancer survivors. Further research is needed to confirm and expand on these findings in different cancer populations, at different stages of cancer (e.g. metastatic, palliative care) and at different stages of the cancer trajectory.

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CHAPTER THREE

PUBLIC DOMAIN BRIEFING DOCUMENT

This document provides an overview of the thesis submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. This document summarises both a literature review and an empirical paper.

Literature review

Illness perceptions and psychological well-being in female cancer patients. A systematic review.

Background: Cancer is among the leading causes of death worldwide. Improvements in the detection and better treatments have led to a rise in the number of people affected by cancer (DeSantis et al., 2014) and the rates of cancer survivors are increasing each year (Maddams et al., 2008). A diagnosis of cancer has a large impact on a number of areas of a woman's life including mental health, quality of life, relationships and employment. Research in female cancer patients shows that to support cancer patients' well-being it is important to understand patients' beliefs about their illness and the way in which they cope with their illness (Cameron et al., 2005; Scharloo et al., 2005). To do this we can draw on health psychology models. One such model is Leventhal's Common Sense model (CSM). According to this model, when a person is faced with a health threat, they create beliefs about their illness, which enable them to make sense of their symptoms and guide any coping actions (Hale et al., 2007). These in turn have an impact on the person's well-being (Leventhal et al., 2005).

Aim: The aim of this literature review was to understand how women's beliefs about their cancer impact on their well-being (e.g. mental well-being, relationships, ways of coping and quality of life).

Method: A systematic search was undertaken to identify studies that looked at women's beliefs (perceptions) about their illness (cancer). After screening, 16 studies were chosen to be included in the review. Relevant data about each study (e.g. study design, type of questionnaire used to measure the illness perceptions, type of cancer) were extracted, and the quality of each study was also assessed.

Findings: The review found that there are some types of beliefs people hold about their illness (related to the identity, cause, control, consequences and timeline of the illness) that are more frequently studied compared to other types of beliefs (e.g. coherence and emotional representations of the illness). There are also some aspects of women's well-being that are more frequently studied (e.g. psychological distress).

The review found that more positive beliefs about the identity of the illness, the timeline of the illness, the consequence of the illness, the causes of the illness and control beliefs about the illness were related to greater psychological well-being. The results of the review were difficult to generalise due to little overlap between the various aspects of well-being and types of illness perceptions looked at across studies.

Conclusions: Different types of well-being (psychological distress, coping, quality of life, social and emotional support and changes in health practices) were found to be related to one or more types of illness perceptions in women with cancer. Given the complexity of the overall picture, comparison across studies was challenging. Further research is needed to clarify these findings and fill gaps in the current published research.

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Empirical Paper

Illness perceptions, resilience and psychological well-being in cancer survivors

Background: Over 331,000 people were diagnosed with cancer in 2011 in the UK (Cancer Research UK, 2014). Improvements in the detection and better treatments have led to a rise in the number of people affected by cancer (DeSantis et al., 2014) and the rates of cancer survivors are increasing each year (Maddams et al., 2008). A diagnosis of cancer has a large

impact on a number of areas of a person's life including mental health, quality of life, relationships and employment. The NHS Cancer Reform Strategy (Department of Health, 2007) stresses the importance of social and psychological support for cancer survivors in order to resume 'as normal a life as they can'. Some people experience higher levels of distress than others (Moskowitz, 2010). Resilience, the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma (Windle, 2011) can be seen as a protective factor against distress (Sharpley et al., 2014; Ryu & Yi, 2013; Min et al., 2013; Luthar & Cicchetti 2000). Additionally, research shows that to support cancer patients' well-being it is important to understand their beliefs about their illness (Cameron et al., 2005; Scharloo et al., 2005). When a person is faced with a health threat, they create beliefs about their illness (also called illness perceptions, cognitive representations or schema), which enable them to make sense of their symptoms and guide any coping actions (Hale et al., 2007). These in turn have an impact on the person's well-being (Leventhal et al., 2005).

Aim: The current study explored the relationship between cancer patients' beliefs about their illness, their resilience and mental well-being.

Method: Cancer patients who had received cancer treatment within the previous eight months were asked to complete questionnaires including questions around their illness perceptions, resilience, quality of life and mental well-being.

Findings: Data from two hundred and forty-seven cancer survivors (135 male, 112 female) were included in the study. The results showed that cancer patients' resilience was important in relation to their psychological well-being and better quality of life following cancer treatment. The findings also showed that more positive beliefs about the consequences of the illness and more positive beliefs in treatment control were related to better psychological

well-being and greater quality of life. Furthermore, patients' emotional responses to having cancer (emotional representations) were also significantly related to mental well-being (positive emotional responses predicted a greater psychological well-being).

Conclusions: Results support previous findings that suggest that resilience is related to quality of life and psychological well-being in cancer patients. Significant relationships were found between negative illness perceptions, poor quality of life and low mood. Cancer patients may benefit from psychological support to address negative beliefs about their illness and increase psychological resilience. Further research is needed to confirm and expand on these findings.

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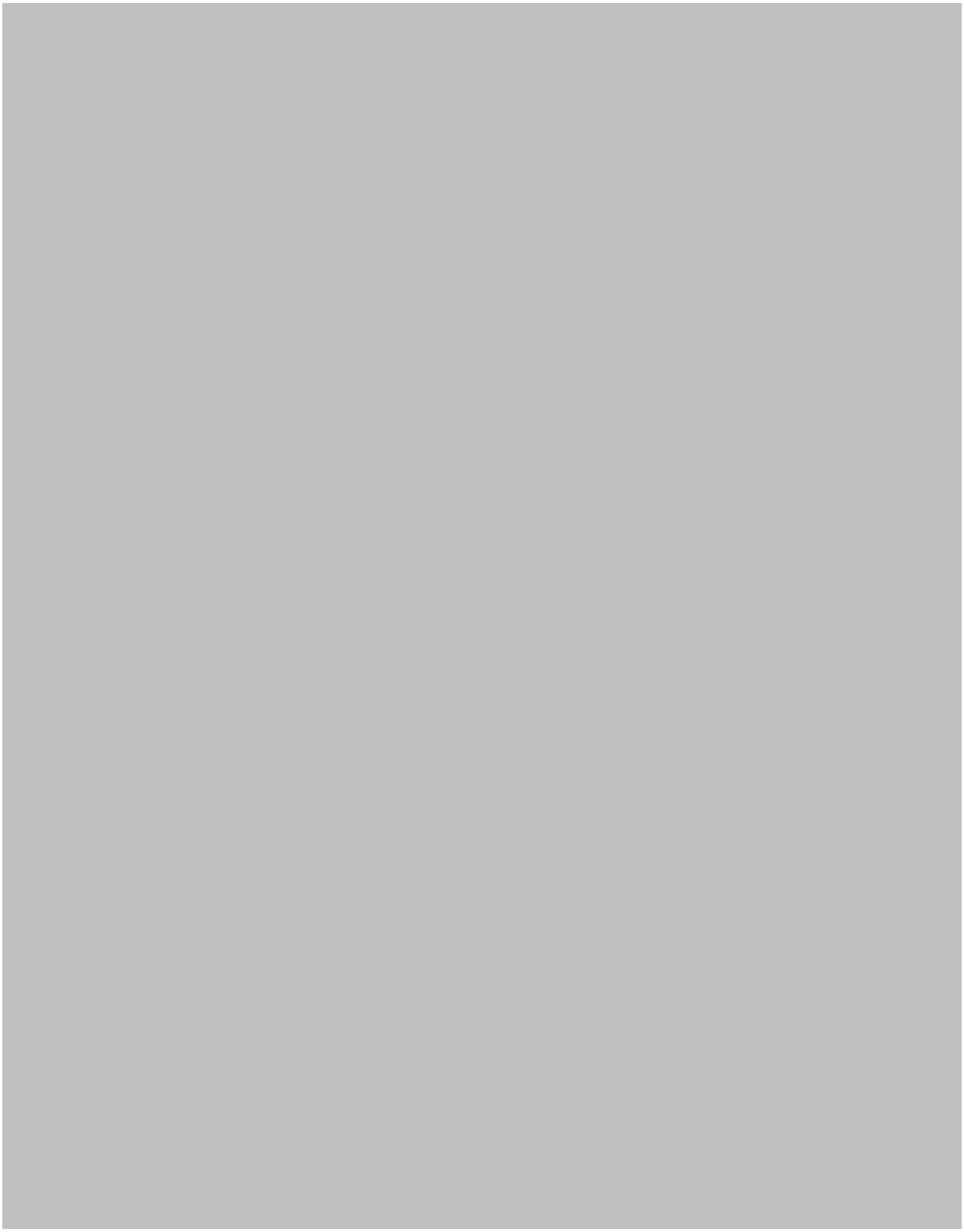
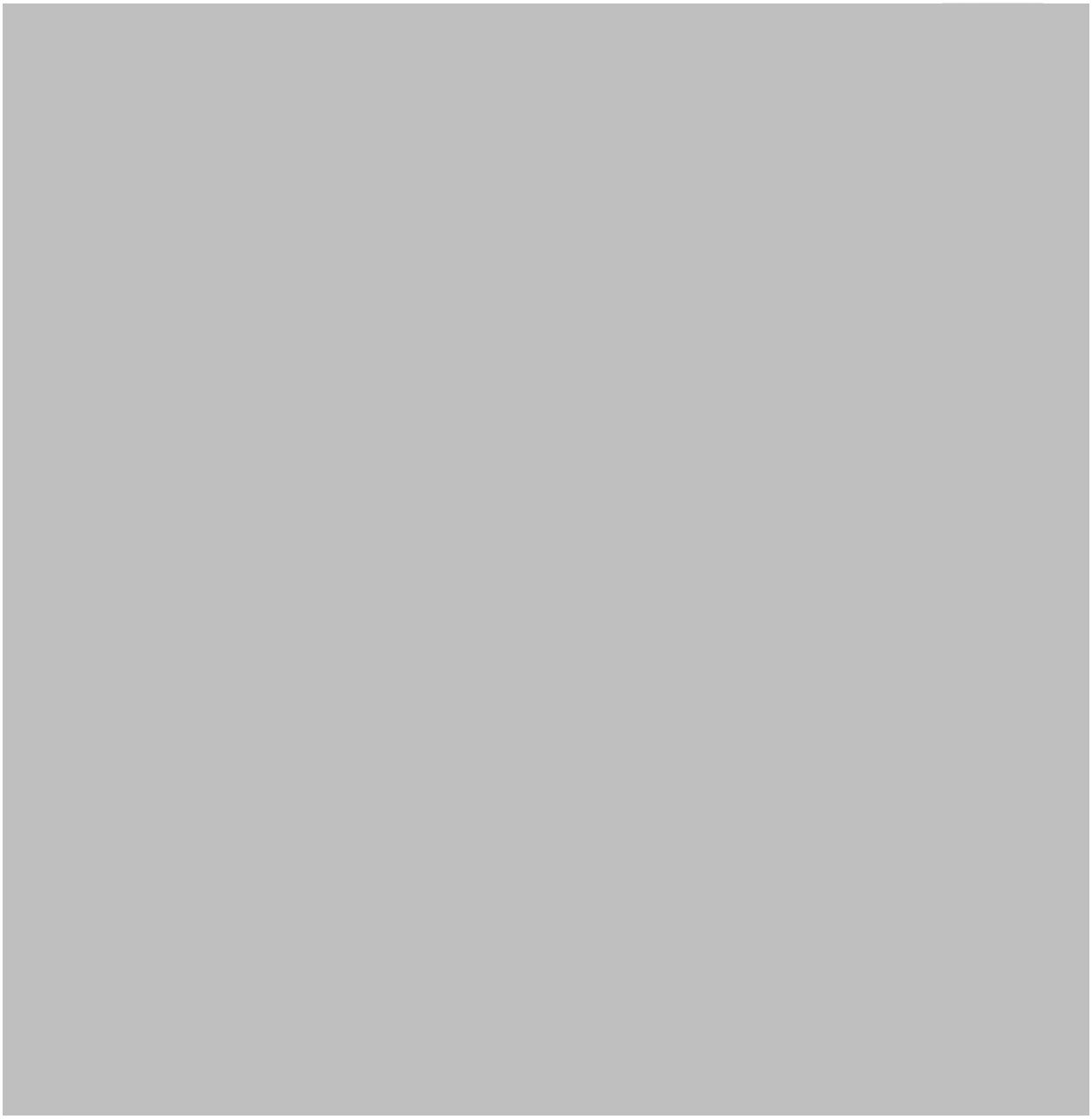
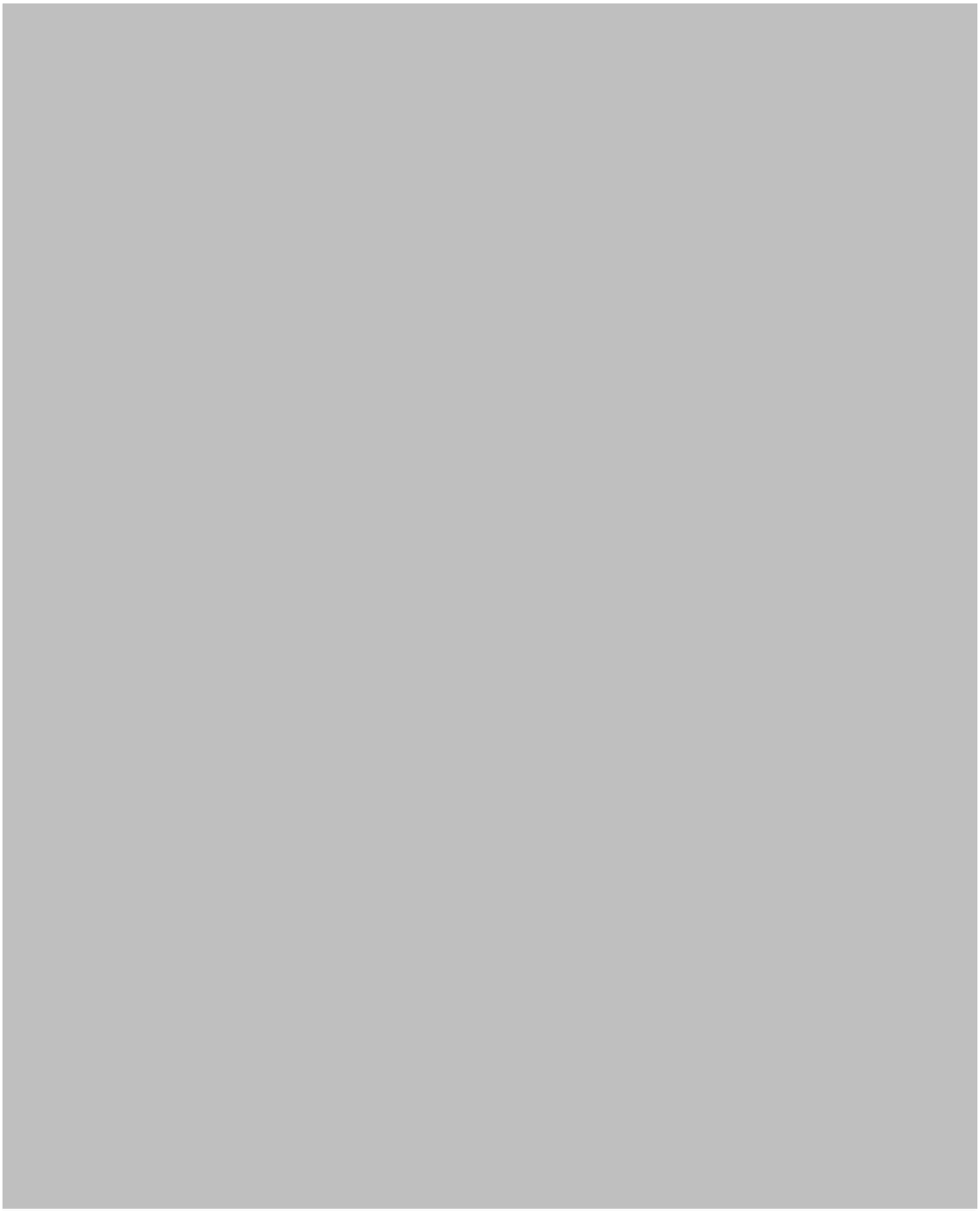
APPENDICES VOLUME I

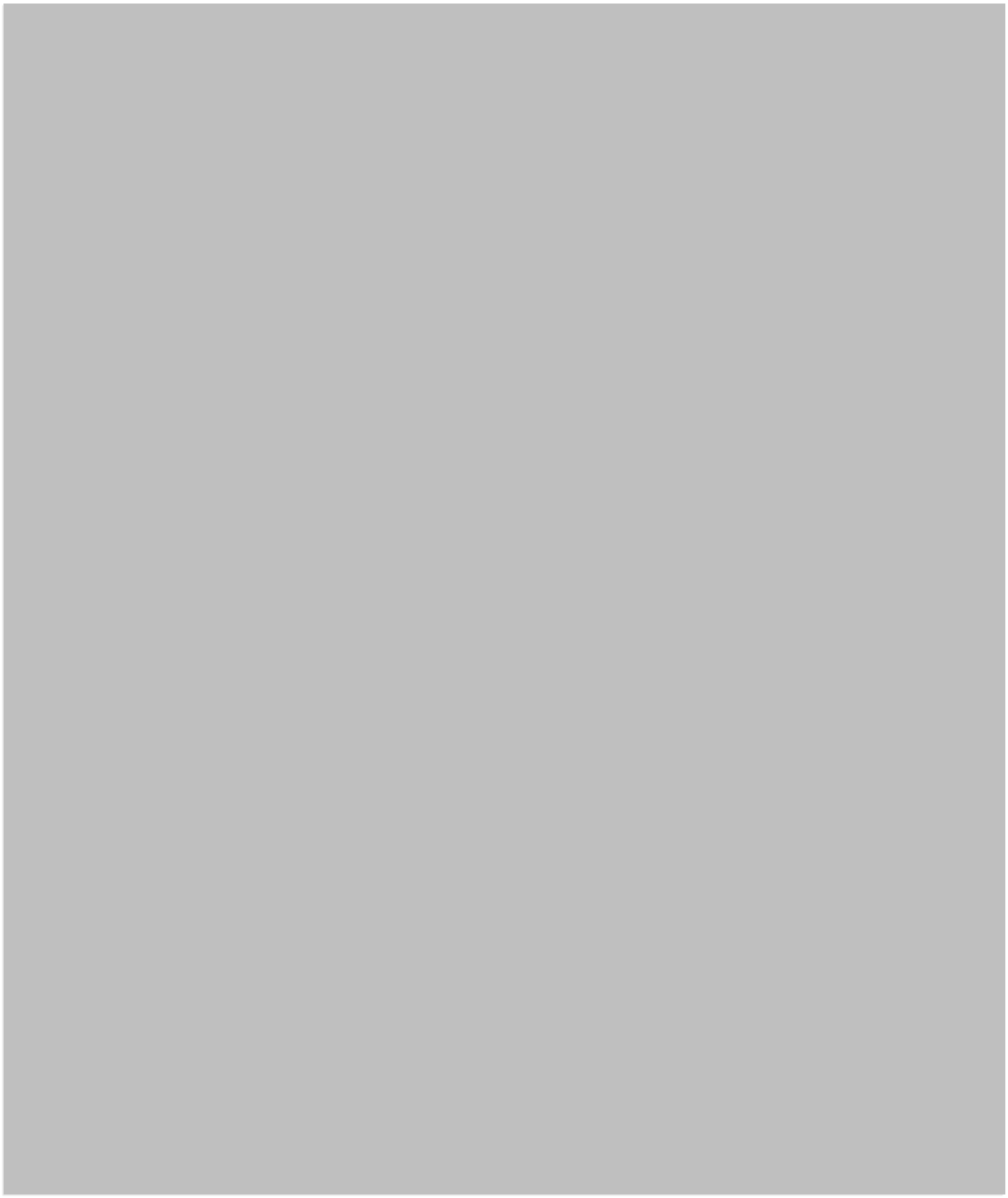
Appendix A - Checklist for assessing the quality of quantitative studies (Kmet, Lee & Cook, 2004)



Appendix B – Local research ethics approval letter







Appendix C

Hierarchical multiple regression analysis for the predictors of quality of life (Global Health Scale) in prostate cancer patients

Step/predictor	R^2	Adjusted R^2	F	β in final equation
1. Demographic and clinical factors	.024	-.022	.527	
Age				.54
Surgery				.70
Chemotherapy				.69
Radiotherapy				.13
2. Self-regulation model	.081	-.036	.694	
Consequences				-.17
Emotional representations				.04
Timeline				.07
Treatment control				.07
Coherence				.17
Personal control				.08
3. Resilience	.221	.111	2.01	.46**

*p<.01; ** p<.001.

Appendix D

Hierarchical multiple regression analysis for the predictors of psychosymptomatology (Global Symptom Index) in prostate cancer patients

Step/predictor	R^2	Adjusted R^2	F	β in final equation
1. Demographic and clinical factors	.066	.020	1.44	
Age				-.17
Surgery				-.27
Chemotherapy				.04
Radiotherapy				-.02
2. Self-regulation model	.182	.074	1.69	
Consequences				.08
Emotional representations				.17
Timeline				.10
Treatment control				-.13
Coherence				-.09
Personal control				.03
3. Resilience	.276	.170*	2.59	-.37*

*p<.01; ** p<.001.

Appendix E

Hierarchical multiple regression analysis for the predictors of (Global Health Scale) in breast cancer patients

Step/predictor	R^2	Adjusted R^2	F	β in final equation
1. Demographic and clinical factors	.019	-.031	.376	
Age				.07
Surgery				.10
Chemotherapy				-.01
Radiotherapy				-.10
2. Self-regulation model	.333	.241	3.641	
Consequences				-.25
Emotional representations				-.07
Timeline				-.11
Treatment control				.37**
Coherence				.14
Personal control				-.03
3. Resilience	.338	.237*	3.343	.079

*p<.01; ** p<.001.

Appendix F

Hierarchical multiple regression analysis for the predictors of (Global Health Scale) in breast cancer patients

Step/predictor	R^2	Adjusted R^2	F	β in final equation
1. Demographic and clinical factors	.066	.018	1.368	
Age				-.22
Surgery				-.02
Chemotherapy				.06
Radiotherapy				-.04
2. Self-regulation model	.194	.080	1.706	
Consequences				.31
Emotional representations				.11
Timeline				.005
Treatment control				-.02
Coherence				-.07
Personal control				.02
3. Resilience	.246	.127	2.074	-.24

*p<.01; ** p<.001.

Appendix G - Questionnaire

UNIVERSITY OF BIRMINGHAM

University Hospitals Birmingham NHS
NHS Foundation Trust

Resilience in Cancer Survivors Questionnaire Pack

This study is being undertaken by the Department of Psychology, University of Birmingham in collaboration with Cancer Centre, Queen Elizabeth Hospital Birmingham, University Hospital Birmingham NHS Trust

If you have any questions or concerns please contact:

□□□□□□/□□

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Questionnaire information

This questionnaire is divided into a number of sections with questions examining your beliefs about cancer, your attitudes towards your health and expressing emotions, your resilience and well-being.

Example questions

Please read each section carefully for section specific instructions. Examples of common formats are below:

Example 1

Views about cancer	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1 My treatment will be effective in curing my cancer	1	②	3	4	5

Questions in this table format require you to circle the number that represents how you feel about each particular statement. So if you felt that you disagreed with this question you would circle number 2.

Example 2

How would you rate your overall health during the last week?

1	2	3	4	5	6	7
Very poor						Excellent

Responses to this question require you to circle the number that represents your overall health over the last week. For example if you feel that your health has been very poor over the last week you would circle 1, 2, or 3; if you fell that your health has been good or excellent over the last week you would circle 5, 6 or 7. The specific number you select depends on how you rate your health.

PLEASE TRY TO ANSWER ALL OF THE QUESTIONS

Please state date completed questionnaire _ _ / _ _ / _ _

SECTION 1. Views about cancer – There are no "right" or "wrong" answers to the questions below, we are interested in your own views about cancer rather than what others have suggested to you

Views about cancer	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. From my experience cancer is a serious condition	1	2	3	4	5
2. From my experience cancer has major consequences on life	1	2	3	4	5
3. Cancer makes me feel afraid	1	2	3	4	5
4. From my experience even if you have no more symptoms after treatment, cancer never really goes away	1	2	3	4	5
5. From my experience there is nothing which can help cancer	1	2	3	4	5
6. I have a clear understanding about the cancer I experienced	1	2	3	4	5
7. From my experience there is a lot which can be done to control symptoms	1	2	3	4	5
8. From my experience cancer does not have much effect on life	1	2	3	4	5
9. From my experience cancer strongly affects the way some people see you	1	2	3	4	5
10. From my experience cancer has serious financial consequences	1	2	3	4	5
11. From my experience cancer causes difficulties for those who are close to you	1	2	3	4	5
12. I don't understand the cancer I've experienced	1	2	3	4	5
13. From my experience you get depressed when you think about cancer	1	2	3	4	5
14. From my experience the course of the cancer depends on the individual	1	2	3	4	5
15. From my experience nothing a person does will affect cancer	1	2	3	4	5
16. The cancer I've experienced is a mystery	1	2	3	4	5
17. From my experience a person's actions will have little affect on the outcome of cancer	1	2	3	4	5
18. From my experience cancer will improve in time	1	2	3	4	5
19. From my experience cancer is very unpredictable	1	2	3	4	5
20. From my experience treatment is effective in curing cancer	1	2	3	4	5

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21. From my experience the negative effects of cancer can be prevented (avoided) by treatment	1	2	3	4	5
22. From my experience treatment can control cancer	1	2	3	4	5
23. From my experience a person could expect to have cancer for the rest of their life	1	2	3	4	5
24. The cancer I've experienced does not worry me	1	2	3	4	5
25. The cancer I've experienced doesn't make any sense to me	1	2	3	4	5
26. Cancer is likely to be permanent rather than temporary	1	2	3	4	5
27. From my experience what a person does can determine whether cancer gets better or worse	1	2	3	4	5
28. From my experience you have the power to influence cancer	1	2	3	4	5
29. From my experience when I think about cancer I get upset	1	2	3	4	5
30. From my experience cancer makes you feel angry	1	2	3	4	5
31. From my experience treatment for cancer will remove the disease forever	1	2	3	4	5
32. From my experience cancer makes me feel anxious	1	2	3	4	5
33. From my experience there is very little that can be done to improve cancer	1	2	3	4	5
34. Even if cancer is treated it will always come back	1	2	3	4	5
35. From my experience the symptoms of cancer are puzzling	1	2	3	4	5

SECTION 2. Possible causes of my cancer

There are no "right" or "wrong" answers to the questions below, we are interested in your own views about what could have contributed to causing your cancer rather than what others have suggested to you (including doctors and family)

Contributing causes	No	Yes
1. My cancer was caused by stress or worry	0	1
2. My cancer is hereditary – it runs in my family	0	1
3. My cancer was caused by a germ or virus	0	1

4. My cancer was caused by diet or eating habits	0	1
5. My cancer was due to chance or bad luck	0	1
6. My cancer was caused by poor medical care in the past	0	1
7. My cancer was caused by pollution in the environment	0	1
8. My cancer was caused by my mental attitude e.g. Thinking about life negatively	0	1
9. Family problems or worries caused my cancer	0	1
10. My cancer was caused by overworking	0	1
11. My cancer was caused by my emotional state e.g. feeling down, lonely, anxious, empty	0	1
12. My cancer was caused my ageing	0	1
13. My cancer was caused by alcohol	0	1
14. My cancer was caused by smoking	0	1
15. My cancer was caused by my personality	0	1
16. My cancer was caused by altered immunity	0	1
17. My cancer was caused by pressure at work	0	1

Please list in rank-order the three most important factors that you now believe caused your cancer. You may use any of the items from the box above or you may have additional ideas of your own.

1. .....

2. .....

3.....

SECTION 3. Concern about cancer in the future

In thinking about the past week, please indicate how much you agree or disagree with each statement. There are no right or wrong answers.

	Strongly Agree	Agree	Not Certain	Disagree	Strongly Disagree
1. Because cancer is unpredictable, I feel I cannot plan for the future	1	2	3	4	5
2. I will probably have a relapse in the next 5 years	1	2	3	4	5
3. My fear of having my cancer coming back gets in the way of my enjoying life	1	2	3	4	5
4. I am afraid of my cancer coming back	1	2	3	4	5
5. I am certain that I have been cured of cancer	1	2	3	4	5

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SECTION 4. Your health
Please answer all of the questions. There are no "right" or "wrong" answers.

	Not at all	A little	Quite a bit	Very much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:				
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you lacked appetite?	1	2	3	4
12. Have you felt nauseated?	1	2	3	4
13. Have you vomited?	1	2	3	4
14. Have you been constipated?	1	2	3	4
15. Have you had diarrhoea?	1	2	3	4
16. Have you had trouble sleeping?	1	2	3	4
17. Have you felt weak?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties	1	2	3	4

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For the following questions please circle the number between 1 and 7 that best applies to you

1. How would you rate your overall health during the last week?

1	2	3	4	5	6	7
Very poor						Excellent

2. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

SECTION 5. Emotional expression
This section contains questions asking about how you express emotions.
Please read each of the following statements carefully and indicate how much you agree or disagree with them, by circling the appropriate number on the right. Please answer all questions.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Disagree
1. I think getting emotional is a sign of weakness.	1	2	3	4	5
2. Turning to someone else for advice or help is an admission of weakness.	1	2	3	4	5
3. It is shameful for a person to display his or her weaknesses.	1	2	3	4	5
4. People will reject you if they know your weaknesses.	1	2	3	4	5
5. If a person asks for help it is a sign of weakness.	1	2	3	4	5
6. When I am upset I bottle up my feelings.	1	2	3	4	5
7. When I am upset I usually try to hide how I feel.	1	2	3	4	5
8. I seldom show how I feel about things.	1	2	3	4	5
9. When I get upset I usually show how I feel.	1	2	3	4	5
10. I do not feel comfortable showing my emotions.	1	2	3	4	5
11. I think you should always keep your feelings under control.	1	2	3	4	5
12. I think you ought not to burden other people with your problems.	1	2	3	4	5
13. You should always keep your feelings to yourself.	1	2	3	4	5

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14. You should always hide your feelings.	1	2	3	4	5
15. I should always have complete control over my feelings.	1	2	3	4	5
16. I think other people do not understand your feelings.	1	2	3	4	5
17. Other people will reject you if you upset them.	1	2	3	4	5
18. My bad feelings will harm other people if I express them.	1	2	3	4	5
19. If I express my feelings I am vulnerable to attack.	1	2	3	4	5
20. If other people know what you are really like, they will think less of you.	1	2	3	4	5

SECTION 6. Resilience

Please indicate how much you agree with the following statements as they apply to you over the last month. If a particular situation has not occurred recently, answer according to how you think you would have felt.

	Not True at All	Rarely True	Sometimes True	Often True	True nearly all the time
1. I am able to adapt when changes occur.	0	1	2	3	4
2. I have at least one close and secure relationship that helps me when I am stressed	0	1	2	3	4
3. When there are no clear solutions to my problems, sometimes fate or God can help.	0	1	2	3	4
4. I can deal with whatever comes my way.	0	1	2	3	4
5. Past successes give me confidence in dealing with new challenges and difficulties.	0	1	2	3	4
6. I try to see the humorous side of things when I am faced with problems.	0	1	2	3	4
7. Having to cope with stress can make me stronger.	0	1	2	3	4
8. I tend to bounce back after illness, injury, or other hardships.	0	1	2	3	4
9. Good or bad, I believe that most things happen for a reason.	0	1	2	3	4
10. I give my best effort no matter what the outcome may be.	0	1	2	3	4
11. I believe I can achieve my goals, even if there are obstacles.	0	1	2	3	4
12. Even when things look hopeless, I don't give up.	0	1	2	3	4

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13. During times of stress/crisis, I know where to turn for help.	0	1	2	3	4
14. Under pressure, I stay focused and think clearly.	0	1	2	3	4
15. I prefer to take the lead in solving problems rather than letting others make all the decisions.	0	1	2	3	4
16. I am not easily discouraged by failure.	0	1	2	3	4
17. I think of myself as a strong person when dealing with life's challenges and difficulties.	0	1	2	3	4
18. I can make unpopular or difficult decisions that affect other people, if it is necessary.	0	1	2	3	4
19. I am able to handle unpleasant or painful feelings like sadness, fear, and anger.	0	1	2	3	4
20. In dealing with life's problems, sometimes you have to act on a hunch without knowing why.	0	1	2	3	4
21. I have a strong sense of purpose in life.	0	1	2	3	4
22. I feel in control of my life.	0	1	2	3	4
23. I like challenges.	0	1	2	3	4
24. I work to attain my goals no matter what roadblocks I encounter along the way.	0	1	2	3	4
25. I take pride in my achievements.	0	1	2	3	4

SECTION 7.
In the last 7 days, how distressed have you been by the following symptoms?

In the last 7 days, how distressed have you been by the following symptoms?	Not True at All	A Little Bit	Moderately	Quite a Bit	Extremely
1. Headaches	0	1	2	3	4
2. Nervousness or shakiness inside	0	1	2	3	4
3. Repeated unpleasant thoughts that won't leave your mind	0	1	2	3	4
4. Faintness or dizziness	0	1	2	3	4
5. Loss of sexual interest or pleasure	0	1	2	3	4
6. Feeling critical of others	0	1	2	3	4
7. The idea that someone else can control your thoughts	0	1	2	3	4
8. Feeling others are to blame for most of your troubles	0	1	2	3	4
9. Trouble remembering things	0	1	2	3	4

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10.Worried about sloppiness or carelessness	0	1	2	3	4
11. Feeling easily annoyed or irritated	0	1	2	3	4
12. Pains in heart or chest	0	1	2	3	4
13. Feeling afraid in open spaces or on the streets	0	1	2	3	4
14. Feeling low in energy or slowed down	0	1	2	3	4
15. Thoughts of ending your life	0	1	2	3	4
16. Hearing voices that other people do not hear	0	1	2	3	4
17. Trembling	0	1	2	3	4
18. Feeling that most people cannot be trusted	0	1	2	3	4
19. Poor appetite	0	1	2	3	4
20. Crying easily	0	1	2	3	4
21. Feeling shy or uneasy with the opposite sex	0	1	2	3	4
22. Feelings of being trapped or caught	0	1	2	3	4
23. Suddenly scared for no reason	0	1	2	3	4
24. Temper outbursts that you could not control	0	1	2	3	4
25. Feeling afraid to go out of your house alone	0	1	2	3	4
26. Blaming yourself for things	0	1	2	3	4
27. Pains in lower back	0	1	2	3	4
28. Feeling blocked in getting things done	0	1	2	3	4
29. Feeling lonely	0	1	2	3	4
30. Feeling blue	0	1	2	3	4
31. Worrying too much about things	0	1	2	3	4
32. Feeling no interest in things	0	1	2	3	4
33. Feeling fearful	0	1	2	3	4
34. Your feelings being easily hurt	0	1	2	3	4
35. Other people being aware of your private thoughts	0	1	2	3	4
36. Feeling others do not understand you or are unsympathetic	0	1	2	3	4
37. Feeling that people are unfriendly or dislike you	0	1	2	3	4
38. Having to do things very slowly to insure correctness	0	1	2	3	4
39. Heart pounding or racing	0	1	2	3	4
40. Nausea or upset stomach	0	1	2	3	4
41. Feeling inferior to others	0	1	2	3	4
42. Soreness of your muscles	0	1	2	3	4
43. Feeling that you are watched or talked	0	1	2	3	4

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about by others					
44. Trouble falling asleep	0	1	2	3	4
45. Having to check and double-check what you do	0	1	2	3	4
46. Difficulty making decisions	0	1	2	3	4
47. Feeling afraid to travel on buses, subways, or trains	0	1	2	3	4
48. Trouble getting your breath	0	1	2	3	4
49. Hot or cold spells	0	1	2	3	4
50. Having to avoid certain things, places, or activities because they frighten you	0	1	2	3	4
51. Your mind going blank	0	1	2	3	4
52. Numbness or tingling in parts of your body	0	1	2	3	4
53. A lump in your throat	0	1	2	3	4
54. Feeling hopeless about the future	0	1	2	3	4
55. Trouble concentrating	0	1	2	3	4
56. Feeling weak in parts of your body	0	1	2	3	4
57. Feeling tense or keyed up	0	1	2	3	4
58. Heavy feelings in your arms or legs	0	1	2	3	4
59. Thoughts of death or dying	0	1	2	3	4
60. Overeating	0	1	2	3	4
61. Feeling uneasy when people are watching or talking about you	0	1	2	3	4
62. Having thoughts that are not your own	0	1	2	3	4
63. Having urges to beat, injure, or harm someone	0	1	2	3	4
64. Awakening in the early morning	0	1	2	3	4
65. Having to repeat the same actions such as touching, counting, or washing	0	1	2	3	4
66. Sleep that is restless or disturbed	0	1	2	3	4
67. Having urges to break or smash things	0	1	2	3	4
68. Having ideas or beliefs that others do not share	0	1	2	3	4
69. Feeling very self-conscious with others	0	1	2	3	4
70. Feeling uneasy in crowds, such as shopping or at a movie	0	1	2	3	4
71. Feeling everything is an effort	0	1	2	3	4
72. Spells of terror or panic	0	1	2	3	4
73. Feeling uncomfortable about eating or drinking in public	0	1	2	3	4
74. Getting into frequent arguments	0	1	2	3	4
75. Feeling nervous when you are left alone	0	1	2	3	4
76. Others not giving you proper credit for your achievements	0	1	2	3	4

77. Feeling lonely even when you are with people	0	1	2	3	4
78. Feeling so restless you couldn't sit still	0	1	2	3	4
79. Feelings of worthlessness	0	1	2	3	4
80. The feeling that something bad is going to happen to you	0	1	2	3	4
81. Shouting or throwing things	0	1	2	3	4
82. Feeling afraid you will faint in public	0	1	2	3	4
83. Feeling that people will take advantage of you if you let them	0	1	2	3	4
84. Having thoughts about sex that bother you a lot	0	1	2	3	4
85. The idea that you should be punished for your sins	0	1	2	3	4
86. Thoughts and images of a frightening nature	0	1	2	3	4
87. The idea that something serious is wrong with your body	0	1	2	3	4
88. Never feeling close to another person	0	1	2	3	4
89. Feelings of guilt	0	1	2	3	4
90. The idea that something is wrong with your mind	0	1	2	3	4

SECTION 8. Information about you

1. Are you currently?

Single □ Married/living with a partner □ Divorced/Separated □ Widowed □

2a. Are you currently working?

Full time □ Part time □ Retired □ Homemaker □ Student □

Other (please specify) .....

2b. Occupation..... .....

- Hours worked before the diagnosis: .....

- Hours worked after the diagnosis: .....

3. What is your highest level of education?

No academic qualifications □ GCSE/O-Level/Equivalent □

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A-Level/Equivalent ☐ Degree Level or Higher ☐

Other (please specify) .....

4. Do you...

Live alone ☐ Live with a partner ☐ Live with a partner and children ☐ Live with children ☐

Other (please state) ☐.....

5. Would you describe yourself as....

Black-Caribbean ☐ Indian ☐ Bangladeshi ☐

Black-African ☐ White ☐ Chinese ☐

Black-Other ☐ Pakistani ☐ Other (please specify):.....

6. **Religion:** .....

7. **Date of birth:** .....

8. **Gender:** Male ☐ Female ☐

9. **Country of birth:** .....

10. **Comorbities:**

Have you been diagnosed with any conditions other than cancer? Please state below

.....

.....

Thank you for taking part in our study

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Appendix H - Author Guidelines for Psycho-Oncology